

**FINDING THE PRACTICAL WISDOM OF MOTHERS OF CHILDREN WITH  
DISABILITIES: NARRATIVES IN THE CONSTRUCTION OF  
MOTHERS' LIVED THEOLOGY**

A Dissertation

Presented to

the Faculty of

Claremont School of Theology

In Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

by

Jeongyun April Hur

December 15, 2022





This Dissertation, written by

**Jeongyun April Hur**

under the direction of her Faculty Committee and approved by its members,

has been presented to and accepted by

the Faculty of Claremont School of Theology

in partial fulfillment of the requirements for the degree of

**Doctor of Philosophy**

**Faculty Committee**

Duane R. Bidwell, Chairperson

Grace Y. Kao

Kathleen J. Greider

**Dean of the Faculty**

Andrew Dreitcer

December 2022

## **Abstract**

### **Finding the Practical Wisdom of Mothers of Children with Disabilities: Narratives in the Construction of Mothers' Lived Theology**

by

Jeongyun April Hur

This study seeks to understand and untangle the disability theology of mothers of children with disabilities by analyzing their narratives using the framework of various worldviews of disability that I developed from “Models of disability: A brief overview,” written by Marno Retief and Rantsoa Letšosa in 2018. I develop this framework by applying Don Browning’s approach of understanding modern psychological theories as having theo-religious qualities, and narrative therapy’s relational framework. This study identifies and explores various kinds of worldviews of disability and then, applies the framework of the worldviews into mothers’ narratives. From the framework of various worldviews of disability, I demonstrate that mothers’ lived theology embodies “the living human web”; that is, mothers concurrently employing multiple perspectives of disability. The pliable set of ideologies enable and support mothers’ web of relationships with diverse worldviews and sustains mothers’ ecosystems of relationships that are mostly comprised of various perspectives of disability. It is possible for mothers to have this capacity to hold different worldviews when they are seemingly, and sometimes, theoretically irreconcilable. I argue that this ability is the fundamental feature of mothers’ practical wisdom and that “Mothers’ practical wisdom” enables mothers to negotiate different worldviews and sustain mothers’ living web of worldviews by having incompatible worldviews simultaneously,” I also explore mothers’ practical wisdom’s perspective from care ethics tradition. The primary motivation behind this branched analysis is that I aim to recognize mothers’ practical wisdom as a source of wisdom for practice for not only Christians, but also

those who are not religious or Christian. Lastly, as a pastoral theological reflection, I detailed the ways in which the medical understanding of disability brings benefits to mothers. By means of this framework, spiritual caregiver can be better equipped to apply the psychological and theological schema toward a deeper understanding of mothers' lived theologies. The framework of various worldviews of disability that I provide through my dissertation is especially designed to complement current disability theology's tendency to favor social constructivist and identity understandings of disability. Furthermore, the framework that I propose will serve as a distinctive voice in current disability theology in that it allows us to understand the positive functions of other models, including the medical worldview of disability.

## **Acknowledgments**

It is with deep gratitude that I acknowledge the many people and institutions that helped me create and complete this dissertation. Claremont School of Theology provided an excellent learning environment with its connection with Claremont Graduate University and the Clinebell Institute. I thank Dr. Duane R. Bidwell, the chair of my dissertation committee. Dr. Bidwell through his teaching and his person modeled many things that were beneficial to me and my writing. He taught me how a person and a scholar can precisely and gently communicate, paying close attention not only to the scholarship but to what is going on spiritually and psychologically within oneself as a person. Dr. Bidwell, throughout these important three years, read carefully every one of my drafts and graciously met with me every two weeks via Zoom. In those meetings, he inspired in me freedom of thought and the finding of my own voice and modeled how teaching and the exchange of ideas go in both directions between student and teacher. Writing this dissertation across the ocean from the School, these Zoom meetings provided an integral resource that motivated me to keep working on this project.

Dr. Grace Y. Kao, who walks her talk, has guided me and helped me since I first took her class. I learned from Dr. Kao that her exacting intellect, mental precision, and academic passion result in the deepest form of her care for her students. Dr. Kao inspired in me self-confidence, lucidity in scholarship and a passion for my scholarly goal.

I thank Dr. Kathleen J. Greider. I learned from Dr. Greider how to be humble, and she also taught me to listen carefully and gently as a scholar and as a person. I know that I was very lucky to participate in her last Practical Theology Seminar (2016). In the first year of my Ph.D. program, I had the chance to talk with Dr. Greider, at which time I told her that I intended to

finish this program within four years. Dr. Greider responded to me gently, telling me that it takes time to grow in wisdom and knowledge. Now I understand what that means. Knowledge, especially in theology, in psychology, and in religion, has an intricate relationship with embodiment. The Ph.D. degree is, to me, not simply a degree; it represents a formation of myself into the kind of person I have become. It taught me how I build relationships with people—how I view the world, how I make sense of those who have different perspectives, and how I understand myself in the world. Being surrounded by these scholars and good people was a true blessing for me that I will remember proudly and fondly.

The scholarship of the scholars on my committee has been a great source of inspiration, and I have modeled my own work on theirs.

I thank Dr. Samuel Lee for the support and insights from a psychologist's perspective and for his excellent supervision at the Clinebell Institute while I worked there as a pastoral counselor. The final project that I did for Qualitative Research Method in Practical Theology (2017) became the blueprint for my dissertation.

I also want to acknowledge and thank Alice and Karyn for offering their stories and life experiences as topics for my dissertation. Their openness, honesty, and generosity made this research project possible.

The Louisville Institute provided a generous dissertation fellowship that enabled me to work full-time on this dissertation, for which I am very grateful.

My decision to return to my parents' house in South Korea was one of the unexpected and important choices I made on my academic journey. My parents made sure that I ate well and slept well. This dissertation would not have been possible without my family's support and sacrifices that allowed me to come to this point, and I know this accomplishment would not have

been as meaningful to me if I had not had my family to share the meaning and the joy of this accomplishment.



## Table of Contents

<b>Acknowledgments .....</b>	<b>vi</b>
<b>Chapter 1. Introduction.....</b>	<b>1</b>
Discussion of the Problem .....	4
Discussion of the Thesis .....	8
Thesis .....	10
Methodology and Method.....	11
Pragmatic Aspects of the Research Approach .....	14
Definitions.....	19
Audience .....	28
Scope and Limitation .....	29
Originality and Contribution.....	30
Outline of Each Chapter.....	31
<b>Chapter 2. Literature Review .....</b>	<b>33</b>
Disability Theology .....	35
Antithesis (1970–2000).....	39
Synthesis (from the Year 2000) .....	48
Psychosocial Understanding of Parents Who Have Children with Disabilities .....	56
Theologians’ Understanding of Mothers of Children with Disability .....	66
Genealogy of Hope: The Concept of Hope in Pastoral Theology .....	71
<b>Chapter 3. Methodology .....</b>	<b>79</b>
Practical Theological Method – Revised Critical Correlation (Pastoral Cycle) – Four Tasks .....	79
Qualitative Research – Discourse Analysis, Narrative Research, and Narrative Therapy .....	89
Research Design.....	102
<b>Chapter 4. Mothers’ Relationships with Their Children’s Disabilities:     Thick Descriptions .....</b>	<b>110</b>
Alice’s Story .....	113
Karyn’s Story .....	139
<b>Chapter 5. Mothers’ Lived Theology: Interpretive Analysis.....</b>	<b>157</b>
Part 1. Concepts and Frameworks to Understand Mothers’ Lived Theology.....	159
Part 2. Interpretation: Living Web of Worldviews as Mothers’ Lived theology.....	176
Part 3. Multiple Disability Worldviews That Shape Two Mothers’ Lived Theologies...	180
Pastoral Theological Interpretation: Function of the Worldviews in Mothers’ Lived Theology .....	206
<b>Chapter 6. Prospect for Developing Mothers’ Practical Wisdom as Normative Virtue:     Normative Task.....</b>	<b>222</b>

Mothers' Practical Wisdom .....	223
Mothers' Practical Wisdom as a Communal Resource.....	224
Mothers' Practical Wisdom as Psycho-Spiritual Resource .....	228
Prospects for Developing Mothers' Practical Wisdom as an Ethics of Care.....	232
 <b>Chapter 7. Shaping My Own Meaning of Disability through “Re-Membering” the</b>	
<b>Worldviews: A Constructive Proposal.....</b>	<b>244</b>
Transitional Space as a Therapeutic Space.....	248
The Role of the Caregiver.....	251
Invitation to Tell the Story .....	254
Identifying Worldviews in Mothers' Stories .....	260
Mapping the Influences of the Worldviews.....	265
Evaluation of Worldviews .....	282
Developing Preferred Stories: Re-Membering .....	284
 <b>Epilogue .....</b>	<b>290</b>
 <b>Appendix A. Various Communities and Their Worldviews .....</b>	<b>291</b>
The Medical Worldview of Disability: Disability as a Disease.....	291
The Moral and/or Religious Worldview: Disability as an Act of God .....	296
The Social Worldview: Disability as a Socially Constructed Phenomenon .....	298
The Identity or Affirmation Worldview of Disability (or the Affirmation Worldview) .....	302
The Theological Identity Worldview .....	304
The Human Rights Worldview: Disability as a Human Rights Issue.....	309
The Legal Worldview of Disability .....	312
 <b>Bibliography .....</b>	<b>316</b>

## Chapter 1

### Introduction

“Welcome to Holland” is an essay written by Emily Perl Kingsley in 1987. It is one of the first and most popular writings that new mothers of children with Down syndrome were given to read as a preparation for facing and raising their children with this disability. Kingsley describes parents of children with disabilities as those who plan to visit Italy but accidentally, contrary to their wills, end up visiting Holland. Parents experience surprises, full of unexpected twists and turns, and loss of their initial dreams and whatever joyful anticipation they had about visiting Italy. Kingsley offers words of wisdom that this pain will probably never entirely go away “because the loss of that dream is a very, very significant loss.”<sup>1</sup> However, Kingsley strongly reminds parents that they may miss the “very special, the very lovely things ... about Holland,” if they focus on the fact that they are not in Italy.<sup>2</sup>

The metaphor of immigration used in the essay well illustrates what I consider the experiential position of mothers of children with disabilities that I observed while interacting with them—either in a clinical setting at the Clinebell Institute for Pastoral Counseling and Psychotherapy or in a qualitative-research setting during my Ph.D. program at Claremont School of Theology. As a non-disabled person who has been familiar with the medical and economic understanding of ‘disability,’ who also wanted to better understand that condition, I thought there must be something that I could learn from mothers of children with disabilities because of their position ‘in-between.’ More specifically, mothers of children with disabilities serve as bridges to

---

<sup>1</sup> Emily Perl Kingsley, “Welcome to Holland,” 1987, [https://www.dsasc.ca/uploads/8/5/3/9/8539131/welcome\\_to\\_holland.pdf](https://www.dsasc.ca/uploads/8/5/3/9/8539131/welcome_to_holland.pdf).

<sup>2</sup> Kingsley, “Welcome to Holland.”

the world of disability in that they can understand some of the inevitable misconceptions and misunderstandings held by able-bodied persons while at the same time they have personally experienced the challenges and agonies of being a parent to a disabled person.

This way of conceptualizing is possible because, inevitably, we live in a society where it is all too easy to draw a boundary between people with disabilities and people without disabilities. In fact, this binary identification gives rise to many problems, as scholars Deborah Creamer and Sharon Barnartt point out.<sup>3</sup> In addition, this social categorization of disability is, to some degree, an arbitrary categorization constructed most likely for the benefit of non-disabled people, as argued by the social model of disability. It does not reflect the diverse range of different human physical embodiment. Still, even if this binary construction of disability is insufficient, it is important to value the experiences of those who are trapped in the in-between. Particularly, for mothers of children with disabilities, this perspective has the potential to provide resources to better understand those who are at the end of this continuum as well as to place greater emphasis on the scarcity of this type of knowledge in the literature.

Before going further, let me break down how I conceive disability. I view disability as a fundamentally natural phenomenon. I distinguish this definition of disability from alternative meanings, which I will interchangeably refer to as ‘understandings of’ and ‘perspectives on’ disability. Later in the text, these notions will expand into ‘worldviews.’ Different meanings of disability reflect individuals’ diverse methods of interpretation. People’s desires, hopes, and dreams are imbued with various meanings of disability, and, in turn, the phenomenon becomes a culture of its own. For example, the medical perspective of disability was criticized for

---

<sup>3</sup> Deborah Beth Creamer, *Disability and Christian Theology: Embodied Limits and Constructive Possibilities* (New York: Oxford University Press, 2009); Sharon N. Barnartt, “Disability as a Fluid State: Introduction,” in *Disability as a Fluid State*, ed. Sharon N. Barnartt, Research in Social Science and Disability 5 (Bingley, UK: Emerald Group Publishing, 2010).

essentializing disability and locating it in the human body, which prompted a social understanding of disability. However, I see the medical perspective less as an idea that focuses on essentialization of disability and more as a culture, a whole worldview of itself. In this vein, the medical perspective is just one kind of interpretation of what naturally transpires in the human body.

This is a somewhat different approach to understanding the contrasting perspectives of disability. Disability theology has focused on evaluating the most theologically sound understanding of disability, for example, seeing the value of the ‘being’ instead of the ‘doing’ of those who have disabilities and critiquing the medical perspective on disability. While following this ‘being disabled’ approach inevitable problems arose. Upholding one perspective as a ‘truth’ held within a large community inevitably leads to neglectful behavior toward what various understandings of disability *do* for people in their lives, especially to those who engage in providing care for those who have disabilities.

By describing and analyzing the employment of various understandings of disability in mothers’ lives, I will show the functions of several views of disability and argue that these functions – pragmatic, psychological and spiritual – are also important factors that must be considered alongside the theological soundness of the idea of disability itself. I argue that the breadth and depth of theological studies as a field is broad enough to embrace various understandings of disability and pastoral theology when employing a care ethics approach.

Through this method, I argue that it can be a beneficial form of ‘practical wisdom’ and has potential to be considered as “care ethics” that includes multiple understandings of disability and is well able to use them when they are needed according to how they support mothers of children with disabilities. Theoretically, some worldviews can lead to conflict, but that wasn’t

necessarily true for my two research partners. The dynamic of different worldviews was to some degree similar to cultures. Encounters with distinct cultures can cause conflicts, but at the same time, they can create synergy; shifting dynamics of different worldviews of disability can also create synergy despite arising from conflicts. Just as the interactions of different cultures and religions can shed light on various aspects of human nature, diverse worldviews on disability, when combined with wisdom and care, can enrich our understanding of what it means to be human beings and the mothers of children with disabilities.

### **Discussion of the Problem**

The topic that I have been investigating is what are mothers' disability theologies, especially when they have children with disabilities, and how mothers' disability theologies can be understood in the contexts of theological and spiritual care.

As I mentioned in the previous section, since I became a Ph.D. student, I explored this topic and consistently found a gap between the literature and what I observed in clinical practice while counseling children with mental disabilities and their parents. Interacting with parents of children with disabilities allowed me to pinpoint the significant disparities surrounding the gap between the experiences of these mothers and the scholarly literature on disability. The most consequential problem that I recognized was that while vast theological norms were provided by theologians to understand disability, these theological norms were not conducive to providing spiritual, psychological, or emotional support for these mothers. Specifically, there are three problems regarding parents of children with disabilities in theological and psychosocial literature.

First, there continues to be a serious limit to the amount of literature in theology that focuses on mothers of children with disabilities. Theological discussion so far has been primarily

centered on disability in general and demonstrates concern for inadequate responses toward disability. In the literature, these parents' efforts as primary caregivers are, at best, underplayed. As such, the current theological understanding of disability is insufficient to adequately address the specific context of the parent-child relationship. In this situation, when mothers' theology is less frequently addressed and analyzed, it can place mothers in difficult positions where the support they are able to receive is far from sufficient. In a similar vein, mothers of children with disabilities were classified or coded more often as caregivers in the literature rather than human beings in need of careful, individual attention themselves.

That said, this theological prescription fails to present a reliable causal argument of and method for understanding disability, as this perspective cannot be feasibly transferred to parents either in clinical settings or in real life. At the crux of this lack of transferability lies a fundamental problem: the normative stance offered in disability theology was neither convincing nor relatable for mothers whom I met in clinical contexts. I could not even fully embrace these ideas myself. There was a glaring gap between the literature and reality. Theological evaluation of disability theologies was not congruent with the conceptualizations and applications of mothers themselves – that is, how mothers evaluate and employ different understanding of disability. Mothers employ worldviews that enable them to connect to social networks, gain social support, and obtain pragmatic benefits. Unlike theologians' evaluations, which reject the medical worldview on disability, the medical worldview was one of the most prevalent worldviews of disability, in conjunction with others, to my research participants.

While the medical understanding of disability, which locates disability in the individual, was most likely discouraged in theological circles, this rejection of the perspective fails to acknowledge many integral aspects of mothers' lives. The medical understanding of disability

functions as a quasi-religious worldview, and it brings crucial pragmatic benefits while also connecting mothers to larger communities and to society as a whole. For these reasons, mothers cannot help but to hold onto the medical understanding, although it may be insufficient – both theoretically and theologically – to understand disability. In light of this fact, theological solutions are nearly pointless for mothers unless at least equal attention is placed on why mothers cannot help but adhere to the medical understanding of disability and its pragmatic benefits and consequences. Without understanding mothers’ realities and how different understandings of disability work in their lives, promoting theoretically and theologically “correct” understandings of disability can serve as a source of guilt among mothers and as yet another source of oppression for them. Moreover, these restrictive, insufficient views can exacerbate the societal challenges these mothers are already experiencing. For this reason, research to examine mothers’ lived theology, especially regarding disability, is necessary.

Second, mothers who are not disabled but experience disability through their children can generate unique theological insights that can expand the horizons of disability theology, especially in that these perspectives could enlighten non-disabled people who were never offered opportunity to experience disability closely. The lack of these valuable perspectives has been shared or highlighted in the literature. Such wisdom may come from mothers who experience two different countries by ‘immigrating to Holland,’ to use Kingsley’s metaphor. Because of their in-between experiences, the experiential insight of mothers can complement current disability theology.

For example, exploring the meaning of disability is a main enterprise of disability theology. As a topic I will address in the literature review, the discipline of disability theology broadly focuses on evaluating the existing understandings of disability before creating and



establishing a new one. Meanwhile, theologians operate under the assumption that there should be ‘only one’ particular disability theology and that when understandings of disability are theoretically contradictory, they cannot exist at the same time.

Sociologist Sharon Barnartt posits a fluid meaning of disability in her book *Disability as a Fluid State*.<sup>4</sup> Barnartt’s understanding of disability as a fluid state is the closest to what I have observed as accurate when considering the necessity to take account of mothers’ experiences and understandings of disability. Later, I have attempted to delve into the dynamics of the fluidity that various meanings of disability create and how that fluidity manifests in the lives of my research participants. Through my use of narrative-based qualitative research, I argue that the fluidity mothers create is a product of their ‘wisdom.’ Based on this notion, I create a framework to better pinpoint and understand the maps of mothers’ disability theology. While doing so, I also propose that the field of disability theology has ignored the complex reality of the functions of mothers’ theological ideas.

Thirdly, I identified a profound gap in the psychosocial literature describing parents’ experiences that obstructs a comprehensive understanding of what parents of children with disabilities encounter. As we will see in Chapter 2, the psychosocial literature describes mothers’ experiences with linear stages. I will refer to this specific process as the ‘dominant discourse’ of parents of children with disabilities. It is undeniable that parents do find a sense of relief by making sense of their experiences through this stage-related process: Anomic-Seekership-Advocacy.<sup>5</sup> However, this linear progression model is flawed in that the stages are not mutually exclusive. They overlap or even two or even three separate stages may coalesce, as I found in the narratives of my research participants. Furthermore, when mothers utilize certain understandings,

---

<sup>4</sup> Barnartt, “Disability as a Fluid State: Introduction,” 2.

<sup>5</sup> Rosalyn Darling, *Families against Society: Reactions to Birth Defects* (Newbury Park, CA: SAGE, 1979).

unlike what stage-center description illustrates, this process is not linear but rather spontaneous, depending on the social circumstances.

The proliferation of this dominant discourse gives rise to tensions because this representation can become a norm or a bathometer that judges, or in extreme cases, oppresses or forces parents to be conventionally “good parents” of children with disabilities. Parents may begin to feel that they have different expectations and experiences that were not addressed. This is partly due to contextual changes; the dominant discourse of parents of children with disability was created in the 1970s. Since then, disability studies have developed exponentially in tandem with a growth in positive legislative changes and social awareness. Parents in the 2020s are likely to have different assumptions and experiences in regard to disability as compared to parents in the 1970s. This different historical context limits the utility of the dominant discourse I identified, making it all the more important to create a new framework to better and more accurately understand parents’ experiences.

### **Discussion of the Thesis**

My dissertation focuses on understanding the lived theology of mothers of children with disabilities. Theology provides a perspective on one’s worldview; the structure of one’s perspective encompasses what one understands about being a human being; understanding provides insights into what is happening in one’s life; insights indicate the significance of what one is doing, and so on. In consideration of this conceptual flow, I ask the following questions in my dissertation: What kinds of disability theology are mothers employing? How do mothers’ lived ‘disability’ theologies influence their lives? In order to clearly distinguish mothers’ understandings of disability, I develop and utilize a framework of worldviews of disability.

Contrary to the broad consensus developed in the field of disability theology and in psychosocial literature, the two mothers involved in my study demonstrate how they employ various understandings of disability because of the various spiritual, pragmatic, and practical benefits they offer. That is, wielding different meanings of disability is, at times, an inevitable and pastoral practice. For example, many different understandings of disability function as bridges for mothers to create and sustain their social networks – a “living human web” that I will later refer to as a “living web of worldviews.” Within this context, I argue the following: 1) For mothers, disability theologies exist in variations that can coexist; 2) Each distinct model exists and is utilized because of its positive functions; and 3) The framework of various intersecting models of disability can serve as an effective therapeutic tool for pastoral care and counseling that reflects mothers’ lived theologies regarding disability, especially via narrative therapy. These variant understandings of disability theologies are, to some degree, constructed to suit various needs of both mothers and their children – from pragmatic to spiritual needs.

When considering the interactive and overlapping nature of the vast number of worldviews, what caught my attention was that many spiritual resources provided to mothers are actually presented by virtue of maintaining a medical perspective of disability, especially when there is prominent lack of moral and emotional support for mothers. For example, as other studies found, medical diagnosis or advice they receive from medical professionals in an early stage becomes a source of affirmation or relief to their doubt and fear of not knowing what is going on with their children and to their self-doubt of becoming a ‘bad parents.’ Mothers shift, modify, and tinker with the various models they subscribe to quite freely. And this, I argue, is mothers’ practical wisdom and has potential to be considered as care ethics.

Based on this observation and analysis, I develop a framework of understanding disability in conjunction with “Models of disability: A brief overview,” written by Marno Retief and Rantoa Letšosa in 2018.<sup>6</sup> Retief and Letšosa categorize nine understandings of disability as models of disability.<sup>7</sup> I develop these models into ‘worldviews’ by adding insights from Don Browning and John Patton. Through this framework, I argue that it is advantageous to maintain various worldviews of disability simultaneously because the practice is beneficial psychologically, spiritually and pragmatically for mothers. Lastly, as a means to delineate and encourage mothers’ practical wisdom and pastoral practice, I offer a narrative therapy guideline.

## **Thesis**

This project is a narrative research study of mothers of children with disabilities in the contemporary United States that aims to enable scholars to identify the various understandings of disability operating simultaneously in mothers’ lived theologies. This study aids in the expansion of Christian theology, specifically disability theology, and of practical and pastoral theology. As such, the intention of this study and work is to establish useful pastoral care and counseling guidelines for those who work with these parents.

## **Methodology and Method**

Under the employment of practical theological hermeneutics with revised critical correlation as a framework to construct dialogue between mothers’ lived theology and literature,

---

<sup>6</sup> Marno Retief and Rantoa Letšosa, “Models of Disability: A Brief Overview,” *HTS Theological Studies* 74, no. 1 (2018): 1–8, <https://doi.org/10.4102/hts.v74i1.4738>.

<sup>7</sup> I will briefly introduce the most commonly used models in the section on definitions in this chapter and more extensively in appendix A.

the qualitative methods of narrative inquiry, discourse analysis and narrative therapy inform the way I interpret mothers' experiences. I examine two mothers' experiences. In doing so, there is one significant issue that needs to be addressed: To what degree are *two* mothers' stories sufficient for eligible research? How can I justify that these two mothers' stories are valuable and valid source of knowledge? It is necessary that I provide an answer to the question on reliability of two people. One of the common questions that can be raised to my dissertation is whether two people are sufficient. This has been a common concern, especially on the research that uses methodologies such as case study or narrative study where study is done for only a few people. In other words, the general assumption is that a few people's experiences is not sufficient. There are three ways to justify the validity of data from my dissertation. I will explain from the less strong argument.

First, to respond to this concern, some scholars assert that these methodologies are apt for generating an assumption, so it is eligible in so far as this is preliminary research. My dissertation, seen from the perspective of a larger trajectory, can also be regarded as a preliminary work; it generates hypotheses that I can further research. Bent Flyvbjerg argues, "The case study is useful for both generating and testing of hypotheses but is not limited to these research activities alone."<sup>8</sup> He points out that the significance of qualitative research with fewer cases is far beyond simply producing hypotheses.

Second, when a person is concerned about the lack of numbers of participants, it is mostly because of the lack of generalizability and notable particularity. However, there are two ways that data from a few people can be valid. First is through the connection the particular case made with the larger issue. This in Flyvbjerg's term is "falsification." Using the famous argument

---

<sup>8</sup> Bent Flyvbjerg, "Five Misunderstandings about Case-Study Research," *Qualitative Inquiry* 12, no. 2 (2006): 222.

of Galileo, Flyvbjerg argues that creating generalizability is not the only way of gaining knowledge; it is only one way. And that even in science, it isn't the random selection of cases that guarantees accurate knowledge; it is the carefully selected one case that may provide the ground on which to create knowledge. Flyvbjerg references Karl Popper's suggestion and use of falsification and asserts that "the case study is ideal for generalizing using the type of test Karl Popper called as Falsification."<sup>9</sup> Falsification is,

One of the most rigorous tests to which a scientific proposition can be subjected: if just one observation does not fit with the proposition it is considered not valid generally and must therefore be either revised or rejected.<sup>10</sup>

Further, Mario Luis Small's article "'How Many Cases Do I Need?' On Science and the Logic of Case Selection in Field-Based Research" provides important insights into the selection of a single case or a few particular cases with which I agree and on which my dissertation relies. Small points out the false belief attached to the idea that data from many cases bring about generability. In fact, what matters in choosing cases is not quantity but logic. One alternative Small provided among two is a mechanism that is similar to Flyvbjerg's falsification. It is called extending the extended case method "by which researchers analyze a particular social situation in relation to the broader social forces shaping it."<sup>11</sup> In explaining the extended case method Small brings two sociologists into the discussion. First is Michael Burawoy. In Burawoy's understanding of the extended case method "the case is understood by investigating the larger forces shaping conditions in the case."<sup>12</sup> In this way, what we learn from the specific case is in fact about the society as the research examines the social impact on the case.<sup>13</sup>

---

<sup>9</sup> Flyvbjerg, "Five Misunderstandings about Case-Study Research," 220.

<sup>10</sup> Flyvbjerg, "Five Misunderstandings about Case-Study Research," 220.

<sup>11</sup> Maria Small, "'How Many Cases Do I Need?' On Science and the Logic of Case Selection in Field-Based Research," *Ethnography* 10, no. 1 (2009): 9.

<sup>12</sup> Small, "'How Many Cases Do I Need?'" 20.

<sup>13</sup> Small, "'How Many Cases Do I Need?'" 20.

However, Burawoy's extended case method is not sufficient for Small as the research is fundamentally on what the single case implies "about society as whole rather than about the population of similar cases."<sup>14</sup> Further, it is insufficient because although "an interesting development of the *theory* might emerge (emphasis original)"<sup>15</sup> it is less clear whether "empirical knowledge of society would emerge from it."<sup>16</sup>

For this, Small references Clyde Mitchell as someone who can provide a clearer answer and complement Burawoy's extended case method. What Mitchell brings is, from Small's perspective, to focus on ability to uncover the process.<sup>17</sup> That is, to the question 'How do you know the case you have chosen is typical?'<sup>18</sup> Mitchell argues, "Extrapolation is in fact based on the validity of the analysis rather than the representativeness of the events"<sup>19</sup>

The natural question is how to determine that an analysis is 'valid'. To answer, Mitchell contrasts 'statistical inference' from what he variously calls 'logical', 'causal', or (more imprecisely) 'scientific inference'. The former is 'the process by which the analyst draws conclusions about the existence of two or more characteristics in some wider population from some sample of that population...'; the latter, 'the process by which the analyst draws conclusions about the essential linkage between two or more characteristics in terms of some explanatory schema'.<sup>20</sup>

There are two ways to understand the argument in relation to my dissertation. First is in the same line of thinking of Flyberg's falsification and Burawoy's extended case method. As I mentioned in the previous section, the major question that prompted me to begin research on this dissertation is the question that I have had while interacting with mothers of children with disabilities and found that the normative theological understanding of disability wasn't so effective for such mothers, unlike the theologian's intention. With this question in mind, I

---

<sup>14</sup> Small, "'How Many Cases Do I Need?'" 20.

<sup>15</sup> Small, "'How Many Cases Do I Need?'" 21.

<sup>16</sup> Small, "'How Many Cases Do I Need?'" 21.

<sup>17</sup> Small, "'How Many Cases Do I Need?'" 22.

<sup>18</sup> Small, "'How Many Cases Do I Need?'" 22.

<sup>19</sup> Small, "'How Many Cases Do I Need?'" 22.

<sup>20</sup> Small, "'How Many Cases Do I Need?'" 22.

explore mothers' lived theology. From the perspective of falsification, I begin with the assumption that "theologians' understanding of disability is most theological" and the case of two mothers' show that the above assumption is not valid to these mothers. So my assumption changed to 'theologians' understanding of disability is not always theological.' Using Buroway's line of thought, this reasoning enhances our understanding of disability theology operating in our society that sometimes, especially in the case of mothers, this is not always valid. Still, from Small's perspective this is part of generating a hypothesis and but not creating empirical knowledge in and of itself. In order to do so, as I mentioned, we need to fulfill what Mitchell provides; whether the case offers insights on process. In order to show multiple worldviews existing and orchestrating simultaneously, I use narrative inquiry to uncover mothers' narrative. Narrative inquiry is apt to explore few participants' stories because of the innate character and value of narrative inquiry believers. Flybjfer points out that "Good narratives typically approach the complexities and contradictions of real life. Accordingly, such narratives may be difficult or impossible to summarize into neat scientific formulae, general propositions, and theories."<sup>21</sup> In this way, the distinctive narrative mothers bring to my research can generate specific knowledge about their narratives.

Overall, when applying the above factors that make valid the knowledge from fewer cases, my thesis becomes: When mothers have children with disabilities in the society where it has its own preponderance of certain worldviews of disability, mothers' understanding of disability can embody the society's preponderance of understanding of disability as their own understanding of disability.

---

<sup>21</sup> Flyvbjerg, "Five Misunderstandings about Case-Study Research," 240.



## **Pragmatic Aspects of the Research Approach**

This research began as a final project for a course called “Ethnographic Research Method” during 2016. In the beginning, it was a pragmatic choice to conduct ethnographic research on parents of children with disabilities. It was necessary for me to choose what was doable within the time and resources I had. In the process, I learned that parents’ narratives have not received sufficient scholarly attention, especially from theological perspectives. With this in mind, I originally intended to use ethnographic research methods because I wanted to closely observe parental relationships with children. However, in 2020 the COVID-19 pandemic broke out just before I had planned on returning to the United States to launch my ethnographic research study. As a result, I had to reconfigure the focus and methods of my study to an extent and settled on conducting narrative research – an approach that was Zoom-friendly and safe for all parties involved.

### **Research Partners**

I had two research partners I interviewed in English twice via Zoom for about 70 minutes each: Alice and Karyn. During the ethnographic research course I took in 2016, a seatmate from the fine arts department gave me piece of paper with the name and email address of Alice, stating that she was a mother of a child with a disability and would potentially be open to talking with me. During the project I was conducting at the time, I was unable to interview her for reasons I cannot recall now, but I did an interview with Alice later for my “Research Methods in Practical Theology” course in 2017. Since then, we have been friends on Facebook, and I visited her art show at Claremont at one point because of my novice interest in art. Hence, there were a few

opportunities to foster the relationship between Alice and me. I was aware of her job, her ideas that she portrayed through her work, and how her activist identity was infused with her artistic identity.

However, I had no prior connection to Karyn. I received her contact information when I sent an announcement to the email community “Disability Studies in the Humanities” that I learned about from the class I took at the University of California in Los Angeles in the summer of 2018.

At the time, I had not intended to find and recruit only mothers; my original intent was to explore parents’ disability theologies as a whole. However, from previous researchers I learned that, more than fathers, mothers of children with disabilities had the tendency to be open or at least more willing to talk. I do not know whether this is because fathers have fewer thoughts on the subject, because they did not want to share their thoughts, or because of other reasons.

In regard to availability, my prior experiences taught me that not all mothers have the necessary time to participate in study interviews, especially when their children are under 18—especially since mothers were most likely to be involved with caring for their children.

Alice and Karyn are not only professionals and experts in their own fields; they also have social capital and educational backgrounds that provide them with more resources (e.g., time) than other mothers, as well as insights. Although their resources enable them to form and have clearer ideas about experiences, the fact that their children are now adults means that they already possess greater experiential wisdom than those whose children are still under 18. By virtue of having to raise their children to adulthood, both mothers already possess a more holistic wisdom of caregiving. That said, although Karyn’s child is living independently, Alice is still involved in providing care for her child.

Both participants are citizens of the United States and were living in the U.S. at the time of the interviews. Alice is racially ambiguous, which she mentioned in later interviews when she shares her experience of being in the margins due to her race, although she does not disclose her ethnicity. Karyn is Anglo-American.

#### Rapport (Relationality)

I developed fairly good rapport with both research participants and did not feel burdened throughout my time interacting and conducting interviews with them. I outlined and explained all the procedures as carefully as possible and felt the trust my research participants placed in me. Alice had already done one interview with me a few years ago. She arranged for a baby-sitter to watch over her daughter so that she could have time for our interview. She remarked that she enjoyed talking about her ideas and her experiences and that I – the researcher - was very receptive and comfortable to talk to.

When it came time for me to meet with Karyn, she asked if she could cycle while doing the Zoom interview. I said yes, and she began the interview while sitting on her spin cycle. However, as the conversation flowed and she became more invested in the questions I was asking, she stopped cycling and immersed herself fully in the conversation. I felt trust because of the enormous openness and kindness both Alice and Karyn showed during the interview.

#### Self-Reflexivity

One of my research questions that began my Ph.D. program was determining the theological meaning of mental illness. My clinical practice and research question, accidentally, hovered around the issue of disability throughout my years in doctoral program. After some time

of wandering, the lived theology of mothers of children with disabilities became my dissertation topic. I still remember my fear of encountering heaviness before I began contacting mothers and scheduling interviews. While writing my dissertation, I was invited to write a personal essay on why I did research on this very topic. This gave me a chance to reflect more deeply on my past and examine the experiences I have had and the meaning I ascribed to disability as a consequence of specific interactions I have had in the past. I want to share part of the essay here as these anecdotes constitute the image of disability I have had.

When I entered fifth grade, a girl with cerebral palsy was in my class; and I saw that she was usually alone. Some friends told me she lived alone with her grandmother. And I learned that she was two years older than the rest of the fifth graders. Later, as often happens when children become familiar with each other, another girl—who enjoyed exhibiting her dominant and aggressive personality—began to bully the girl with cerebral palsy. As time passed the bullying grew worse. One day, during a break in the class, the powerful girl asked the disabled girl to dance in front of all the students. The girl with a disability refused in the beginning but later felt pressured to perform. When she began to dance and sing, nearly everyone laughed. The girl who performed exchanged attention for humiliation. Those who did not laugh, including myself, did not know how to respond.<sup>22</sup>

In retrospect, I think that these incidents taught me that disability is something that is weak, vulnerable and can be humiliated. The uneasiness and questions continued until I became an adult. I felt that Clare Harvey's psychoanalytic research on the fear and anxiety of non-disabled people in relation to the notion of disability explains my resistance toward disability. Harvey explains that,

The emotional experiences of non-disabled people in relation to disability are in themselves highly complex and often contradictory, causing many individuals to be both fascinated and repelled. Anxiety is the overarching emotion. Watermeyer writes that “disability awakens discomfoting feelings” in non-disabled people, which activates psychological defense mechanisms, which can distort reality and result in a warped perception of the disabled person. Authors in the area suggest that aspects of disability in others, including experiences of vulnerability and dependency, cause non-disabled

---

<sup>22</sup> Jeongyun April Hur, “Facing My Own Fears, Finding Wisdom,” *Reflections* (Fall 2021), <https://reflections.yale.edu/article/divine-access-disability-and-belonging/facing-my-own-fears-finding-wisdom>.

individuals to feel anxious as these aspects are experiences which many people have difficulty with.<sup>23</sup>

The research confirms my own emotional experience and helped me to accept it. I felt relieved since I found the source of resistance and fear. This self-realization made me understand more deeply why mothers cannot rid themselves of their medical or economic understandings of disability, even when these worldviews are not so friendly to their children. Affirming these mothers' fears and sorrows was, also, to affirm mine. It is important to acknowledge the thoughts prevalent in reality, and to understand why it is equally important to create a sound theological understanding of disability.

## **Definitions**

### **Theology**

Theology, for me, requires interpretation and evaluation. It intends to interpret subjects most closely to their intrinsic and existential value and meaning. Because theologians' utmost concern is in the subject's intrinsic and existential value, the truth is essential. I begin with Kathryn Tanner's understanding of the field of theology: "A theologian discusses human beings in relation to God. Discussion of this relation to God is the theologian's contribution to the understanding of human life."<sup>24</sup> Interpreting what took place is also a "reevaluation of the value." Theological interpretation may be re-interpretation because often the subject matter that theologians engaged has already been assigned valued; in other words, it has been interpreted within an available values system, most commonly economics. However, theologians seek to

---

<sup>23</sup> Clare Harvey, "Maternal Subjectivity in Mothering a Child with Disability: A Psychoanalytical Perspective," *Agenda* 29, no. 2 (2015): 92.

<sup>24</sup> Kathryn Tanner, "The Difference Theological Anthropology Makes," *Theology Today* 50, no. 4 (1994): 567.

present the ‘theological perspective.’ Tanner asserts, “Theology, on the basis of its understanding of God, proclaims the objective value of God’s creatures, a value that must, therefore, be respected in the relations human beings establish with one another and with other kinds of beings in the world.”<sup>25</sup> Re-evaluation takes place because theologians attempt to see from God’s perspective. God, here, I think, is not restricted to the Christian God, although Tanner’s article is written from a Christian theological perspective. From my perspective, who this God is, is a secondary matter. The function of the idea of God, here, is to point to the ontological truth of human beings and other beings in the world. In this light, the theological task that I conceive as important is to see the intrinsic value of beings. My dissertation involves theological research in that it seeks to uncover the intrinsic value of disability and experience of disability by undertaking the task of evaluating common thoughts associated with disability through exploring mothers’ experiences.

## Disabilities

As ‘disability’ is one of the most important concepts of my dissertation, it is indeed necessary to define the term. Issues of definition especially for the term ‘disability’ are particularly complicated and can be controversial. This requires some explanation.

I understand disability as a natural, organic phenomenon; it is something that transpires naturally; it is not imbedded with value or meaning. The term, ‘impairment’ will be used when I refer to a value-free physical or mental state of disability. However, I want to differentiate between disability as a physical phenomenon and the different meanings imbued in the term disability. When I use the word ‘disability’ it will mean the natural phenomenon unless I state

---

<sup>25</sup> Tanner, “The Difference Theological Anthropology Makes,” 567.

otherwise. I will interchangeably use ‘disability’ and ‘impairment.’ In that sense, the researcher preserves mothers’ perspectives when they discuss their experiences of disability. When this dissertation refers to disability it refers to the meanings of disabilities.

The meanings of disability are varied, and each meaning is accompanied by its own dynamics that relate to each individual. My position on disability is that although disability itself is fundamentally something that transpires, the social contexts we live in make it inevitable that different people imbue the word with different meanings, according to how they experience its different forms. Given this social reality, I argue that we can benefit by allowing and promoting multiple understandings of disability. A similar argument was made by Susan Barnartt who sees disability as a fluid state. Furthermore, I believe the United Nations also refers to the non-static character of meanings of disability when it suggests that a disability involves an “interaction between societal conditions or expectations and the abilities of the individual.”<sup>26</sup> All this is to say that this dissertation does not hold a particular attachment to any particular meaning of disability such as the medical or social model. There are several reasons why I came to believe in this way. First, it is impossible for us as part of contemporary society to live with only one theological, ideal understanding of disability; practically speaking, it is not possible. Being pragmatic or efficient cannot be the sole reason to determine the meaning of certain concepts. I believe each perspective on disability indicates some truth, some part of human reality, reflects our deepest fears and hopes and dreams about humanity and life that cannot be disregarded. So, I think being able to integrate, or at least to make room to freely integrate, these different worldviews and aspects of disability can enhance and deepen our understanding of disability. Furthermore, being

---

<sup>26</sup> United Nations, *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, Human Rights, Office of the High Commissioner, December 20, 1993, <https://www.ohchr.org/en/instruments-mechanisms/instruments/standard-rules-equalization-opportunities-persons-disabilities>.

able to integrate different worldviews will encourage to understand and embrace people who hold different meanings of disability. However, I will suggest at the end of my dissertation how I think it is most theologically appropriate to think of disability.

I became convinced that defining disability is a matter of “theology” because the concept of disability is usually constructed around and results from individuals’ differing worldviews. Each person brings a personal understanding of how the world is functioning and is meant to function and what values one should and should not pursue. Each understanding of disability is deeply connected with a different ‘theology,’ which, in my dissertation, I present as a worldview. Through using the framework of various models of disability, I was able to see the arbitrariness of the various meanings of disability attached to physical impairment. So here, I want to note what I am clear about at this stage. I will sometimes differentiate an impairment from a disability. By impairment, I mean the physicality of disability, a bodily phenomenon that includes both mental and physical capabilities without meaning attached, as much as possible.

The specific disabilities that I refer to in this dissertation by engaging mothers’ narratives are Spastic Quadriplegic Cerebral Palsy and Cerebral Aneurysm Rupture. Spastic Quadriplegic Cerebral Palsy is considered a neurological disorder, and Cerebral Aneurysm Rupture is listed as an impairment in the Social Security Administration’s impairment listing manual.<sup>27</sup> However, I didn’t want to limit the notion of disability to these two specific types in my analysis and when proposing the framework. When I refer to or explore the notion of “disability” in my dissertation, I am specifically mindful of other kinds of disability, such as mental illnesses. In addition, my

---

<sup>27</sup> “Disability Evaluation under Social Security,” Medical/Professional Relations, Social Security Administration, accessed December 20, 2022, <https://www.ssa.gov/disability/professionals/bluebook/11.00-Neurological-Adult.htm>.



dissertation builds upon the literature that talks not only about physical disability but also about mental illnesses.

### Framework of Disability Theology

The “framework of disability theology” refers to the framework that I have developed in chapter 5, wherein I categorize a number of different understandings of disability with a typological approach, seeing them as worldviews that go beyond the basic definition of disability but also encompass reflection, which includes an interpretation of the world. The framework was developed with the insight discovered from mothers’ lived experiences that I describe in chapter 4 in conjunction with the work of Reteif and Letšosa’s categorization of the nine dominant models of disability prevalent in individuals’ realities. Based on the work of these two scholars, I added some understandings of disability used by my research partners and deleted others that they didn’t use. Through this framework, I intend to help theologians, care givers, and parents identify different levels of disability and the world views within which disabled people operate. Here, I briefly describe eight models or understandings of disability used in this dissertation. In describing these models here in this section, I heavily relied on Reteif and Letšosa’s “Models of Disability: A Brief Overview.”<sup>28</sup>

### The Moral and/or Religious Model: Disability as an Act of God

The moral and/or religious model of understanding disability is that it is an act or a result of God, either as a punishment or a trial. It is one of the oldest ways of conceiving of disability

---

<sup>28</sup> Reteif and Letšosa, “Models of Disability: A Brief Overview.” Please see the more detailed explanation on each worldviews in Appendix A.

and is observed “in a number of religious traditions, including the Judeo-Christian tradition.”<sup>29</sup>

The action that can cause disability as a punishment is “lack of adherence to social morality”<sup>30</sup> or disobeying God. The punishment can be caused by “sin that may have been committed by their parents and/or ancestors.”<sup>31</sup>

On the other hand, in the mystical tradition of Christianity disability can be a sign of blessing because “the fact that one of the senses of a person is impaired inevitably heightens the functioning of the other sense of that person, as well as granting him or her ‘special abilities to perceive, reflect, transcend, be spiritual.’”<sup>32</sup> In this sense, this person is understood to be selected by God.

#### The Medical Model: Disability as a Disease

According to Retief and Letšosa, “From the mid-1800s onwards, the medical model began to gradually replace the moral and/or religious model” due to the outstanding developments that occurred in medical science.<sup>33</sup> Through the lens of the medical model, a disability is considered “a medical problem that resides in the individual. It is a defect in or failure of a bodily system and as such is inherently abnormal and pathological.”<sup>34</sup> Disability is obviously abnormal; due to the medical model’s negative understanding, it is sometimes called a ‘personal tragedy’ model.<sup>35</sup>

---

<sup>29</sup> Retief and Letšosa, “Models of Disability,” 2.

<sup>30</sup> Henderson and Bryan (2011), 7, quoted in Retief and Letšosa, “Models of Disability,” 2.

<sup>31</sup> Retief and Letšosa, “Models of Disability,” 2.

<sup>32</sup> Olkin (1999), 25–26, quoted in Retief and Letšosa, “Models of Disability,” 2.

<sup>33</sup> Retief and Letšosa, “Models of Disability,” 2.

<sup>34</sup> Retief and Letšosa, “Models of Disability,” 2–3.

<sup>35</sup> Thomas and Woods (2003), 15, quoted in Retief and Letšosa, “Models of Disability,” 3.

## The Social Model of Disability: Disability as a Socially Constructed Phenomenon

The social model of disability is developed by the activism of the British disability movement in the 1960s and 1970s as a reaction to the discriminatory limitation of the medical model of disability.<sup>36</sup> It takes a stance opposite that of the medical model of disability by opposing the belief that disability is located within the individual but says instead that it is socially constructed by society. Thus, rather than trying to influence individuals through “adjustment” or “rehabilitation,” the social model focuses on making “societal change.” Due to shared philosophical roots, I interchangeably use ‘the social model of disability,’ ‘the social constructionist perspective’ and ‘the liberationist perspective.’

## The Social Constructionist Perspective

“Social ‘construction,’ ‘constructionism’ and ‘constructivism’ are terms in wide use in the humanities and social sciences and are applied to a diverse range of objects, including emotions, gender, race, sex, homo- and heterosexuality, mental illness, technology, quarks, facts, reality, and truth.”<sup>37</sup> Constructivism is also an epistemological position grounded in the central idea that “‘reality’ is constructed by the observer and is not an external entity entirely separate from the observer.”<sup>38</sup> The essence of the idea of social constructionism is that “some object or objects are caused or controlled by social or cultural factors rather than natural factors, and if there is any core motivation of such research, it is the aim of showing that such objects are or were under our control: they could be, or might have been, otherwise.”<sup>39</sup> The social model of

---

<sup>36</sup> Retief and Letšosa, “Models of Disability,” 3.

<sup>37</sup> *Stanford Encyclopedia of Philosophy*, s.v. “Naturalistic Approaches to Social Construction,” first published Nov. 10, 2008, substantive revision Jan. 11, 2019, <https://plato.stanford.edu/entries/social-construction-naturalistic/> 6\_19\_2022.

<sup>38</sup> J. Paul Gallant, “New Ideas for the School Social Worker in the Counseling of Children and Families,” *Children and Schools* 15, no. 2 (April 1993): 119.

<sup>39</sup> *Stanford Encyclopedia of Philosophy*, s.v. “Naturalistic Approaches to Social Construction.”

disability aligns with the social constructionist perspective, as it sees disability as a socially constructed notion. From my perspective, the social model of disability is best understood from within a broader social constructionist perspective.

### The Liberationist Approach

The liberationist approach means “principles or attitudes advocating liberation.”<sup>40</sup> When disability theology first emerged in Eiesland’s work in the 1980s, Eiesland combined the sociological perspective of disability, that is the social model of disability, with liberation theology with the intention to liberate people with disabilities. When I refer to the liberationist approach, I use it interchangeably with the social model of disability and the social constructionist perspective.

### The Identity Model: Disability as an Identity

The identity model shares the fundamental assumptions of the social model of disability, except that it imbues positive meaning and identity to disability. Disability becomes “a marker of membership in a minority identity, much like gender or race.”<sup>41</sup>

### The Economic Model: Disability as a Challenge to Productivity

The economic model of disability perceives disability exclusively from the perspective of economic analysis, mostly a cost-benefit analysis. It focuses on “the various *disabling effects* of an impairment on a person’s capabilities, and in particular on labor and employment capabilities

---

<sup>40</sup> *Merriam-Webster Dictionary*, s.v. “Liberationism,” <https://www.merriam-webster.com/dictionary/liberationism>, accessed June 28, 2022.

<sup>41</sup> Brewer et al. (2012), 5, quoted in Retief and Letšosa, “Models of Disability,” 5.

(original emphasis).”<sup>42</sup> In other words, the model estimates “a disabled person’s ability to work”<sup>43</sup> and to what degree their labor can contribute to the economy.<sup>44</sup> Often the economic model is used “by governments as a basic point of reference for formulating disability policy.”<sup>45</sup>

### The Limits Model: Disability as Embodied Experience

The limits model of disability was developed by Deborah Creamer in 2009. It states that “disability is best understood with reference to the notions of embodiment and ‘limitedness.’”<sup>46</sup> By offering the notion of limit, Creamer expands the understanding of disability by embracing various kinds of limitation in our daily lives as experiences of disability. As a result, the experience of disability becomes part of human experience, as limits are “a common, indeed quite unsurprising, aspect of being human.”<sup>47</sup> The expansion is intended to avoid binary categorization associated with disability in our society such as ‘disabled,’ ‘able-bodied,’ and ‘abnormal body,’ and ‘normal body’ and to seek ways to acknowledge a shared ground as human beings.<sup>48</sup>

### Children

I am using the term children *relationally* rather than chronologically. Children in my dissertation indicate those who are persons who have been raised by parents, involved in the parental relationship, but not necessarily those in the precise age range of “children” who are

---

<sup>42</sup> Retief and Letšosa, “Models of Disability,” 6.

<sup>43</sup> Smart (2004), 37, quoted in Retief and Letšosa, “Models of Disability,” 6.

<sup>44</sup> Retief and Letšosa, “Models of Disability,” 6.

<sup>45</sup> Jordan (2008), 193, quoted in Retief and Letšosa, “Models of Disability,” 6.

<sup>46</sup> Retief and Letšosa, “Models of Disability,” 6–7.

<sup>47</sup> Creamer (2009), 31, quoted in Retief and Letšosa, “Models of Disability,” 7.

<sup>48</sup> Retief and Letšosa, “Models of Disability,” 7.

minors. Thus, my dissertation does not focus on those who are of ages from 4–12 but includes adult children.

## Parents

In examining parents of children with disabilities, my dissertation will select self-identified parents without discriminating between birth and adoptive parenthood.

## Care Practices

The term “care practices” refers to practices and support involved in parenting children with disabilities. My dissertation will use “parenting” and “care practice as parents” interchangeably.

## Parental Relationship/Pastoral Relationship

Parental relationship and pastoral relationship refer to different things. Parental relationship literally means the relationship between parents and children. Pastoral relationship refers to a relationship that involves care in any human relationship.

## **Audience**

The primary audience of this dissertation is my dissertation committee: Duane R. Bidwell, Grace Y. Kao, and Kathleen J. Greider. The secondary audience is composed of mothers, parents, families of children with disabilities, scholars who are interested in these topics, and professional caregivers of a variety of kinds, including those with particular interest in parents of children and especially those who offer spiritually integrated psychotherapy. The

audience that I have in mind also includes those who don't identify with disability, but, like myself, want to have a sound understanding of it in a way that is intricately related to the meaning of being human.

### **Scope and Limitations**

When it comes to the issue of disability, there are many approaches that can be taken. While other approaches and emphases such as social activism are important, this dissertation narrowly focuses on generating knowledge that can enhance and deepen self-understanding on an individual level and that can be used in interpersonal relationships or in caring contexts, especially the professional counseling setting. I focus on creating knowledge that helps illuminate mothers' disability theologies that can be used by themselves and by those who are in caring professions. The thick description on which I developed the framework of worldviews of disability is drawn from two mothers who are in their fifties. The framework that I offer is to be applied only to this contemporary context. I did not engage factors such as class and gender because of the obvious limited scope of this research, although I do mention the factor of social capital.

The scope of variations of disability and mental illness of children will not be examined in depth. Naturally, when I refer to disability, it must be noted that the framework was drawn out of the experience of developmental disability. The specific disabilities to which I refer here are Spastic Quadriplegic Cerebral Palsy and Cerebral Aneurysm Rupture. However, in the process of researching, writing, and developing this framework of disability theology, I personally experienced that it was also helpful to use this framework to understand and accept mental illnesses such as depression and anxiety. This will be the topic for further research.

## Originality and Contribution

The goal of this dissertation is to generate theological knowledge *in situ*, from a specific location. In my case, this knowledge relates to U.S. American mothers of children with developmental disabilities. To this end, this work is intended *to bring light to the complexity of their experiences* by using a theological vocabulary. By exploring mothers' experiences, I intentionally seek from disability theology the wisdom and/or a strategy that can help explain seemingly irreconcilable ways of understanding disability.

In this regard, this dissertation contributes in three primary ways. First, as the major method used is practical theological hermeneutics, this dissertation shows the use of the practical theological method in the particular case of mothers of children with disabilities. Second, it contributes to two fields: disability theology and the psychosocial literature on parents of children with disabilities by (a) suggesting ways to reconsider disability, especially by reconciling the conflicts within various understanding of disabilities (for example, the medical model and the social model in the theological field) and (b) complementing the psychosocial literature's linear-stage-related model of understanding parents by proposing a new lens through which to view mothers' understanding of disability. Third, it contributes to spiritual care and counseling, care ethics, and narrative therapy by adding the cases of these mothers and offering an interpretation from each of these fields, spiritual care and counseling and care ethics, as well as a practical tool particularly designed for these mothers, that is, a particular approach to narrative therapy. Mothers' understandings of disability theology will be enhanced when they are offered theological and practical resources that equip them to better understand themselves. I intend the result of this dissertation to be a resource for mothers of children with disabilities that can enable them to reflect on their experiences—such as why they think, act, and tell stories the way they do and the reasons



for and the meanings of what they are doing. Also, this project is meant to offer resources for those who are in the caregiving field, for example, psychotherapists or ministers, who help parents to better comprehend their situations and themselves and to feel affirmed.

### **Outline of Each Chapter**

Let me summarize the preceding discussion by highlighting the development of the chapters of this dissertation. Chapter 1, “Introduction” provides a roadmap of my whole dissertation.

Chapter 2, “Literature Review,” traces the way theological understandings of disability, psychosocial understandings of parents/mothers and children with disabilities, theological understanding of parents of children with disabilities and theological understandings of hope have developed in the fields of pastoral/practical theology, disability theology, and psychosocial literature, as my research question crosses these fields.

Chapter 3, “Methodology,” argues that the methodological approaches used in this study – a practical theological hermeneutics of revised critical correlation and narrative research and discourse analysis as qualitative research – are the most apt for framing and developing answers to my research questions. In this chapter I will discuss the strengths and weaknesses of each method, as well as point out how my research will acknowledge and mitigate their weaknesses.

Chapter 4, “Thick Description” presents the results of narrative research, identified and analyzed by themes that emerge from interviews with mothers of children with disabilities. I narrate stories of mothers, drawing on the philosophy of narrative therapy and reflecting on those stories. With these stories, I describe mothers’ understandings and experiences of disability, wholeness, parenting, of themselves as parents, changes in parents’ lives, and more.

Chapter 5 focuses on an interpretive task which I have divided it into two parts. Part 1 focuses on introducing concepts and frameworks of “worldviews” and “community of worldview.” Then in Part 2, employing the aforementioned concepts I demonstrate, in Alice and Karyn’s stories, that the “living web of worldviews” is an important aspect of mothers’ lived theology. That is, multiple perspectives of disability can and do exist simultaneously in mothers’ lived theology.

In chapter 6, I offer normative values from mothers’ experiences: Mothers’ Practical Wisdom. Here, I focus on how the living web of worldview is possible for mothers and argue that the coexistence of perspectives of disability is a result of mothers’ practical wisdom. Mothers’ practical wisdom is situated in the tradition of care ethics and the discipline of pastoral theology as psycho-spiritual resources. A primary reason for this double location is that I wanted mothers’ practical wisdom to be a source of wisdom for the practices of Christians and those who are not religious or Christian.

In chapter 7, I offer a constructive proposal, a guideline of narrative therapy that I believe to be specifically appropriate for mothers of children with disabilities. By offering narrative therapy that is specifically designed for mothers of children with disabilities, my goal is to help mothers to be explicitly aware of their agency and their practical wisdom and thus be empowered to employ these further and more confidently, with intention. I want them to *see* themselves as agents of this activity of “mix and match” of different worldviews of disability which can enhance their sense of self-esteem and to have a chance to enjoy benefits by employing various understanding of disabilities. Finally, mothers and their caregivers need to be convinced that mothers’ practical wisdom is not only possible but good.

## **Chapter 2**

### **Literature Review**

In this chapter, I review some of the historical influences that have helped shape the perspective from which I understand mothers' lived experiences and lived theologies. This section is divided into four parts: "Disability Theology," "Psychosocial Understandings of Parents Who Have Children with Disabilities," "Theologians' Understandings of Mothers of Children with Disability," and "Genealogy of Hope: The Concept of Hope in Pastoral Theology." Broadly, the first three sections offer contexts within which to understand, respectively, mothers' knowledge of and response to disability, how experiences of parents of children with disabilities are understood, and the theological interpretation of mothers' experiences. Unlike these first three sections, section four presents a genealogy of hope which will offer theories or frameworks within which to analyze the hopes of two mothers, my research partners, and various worldviews of disability.

In the section on disability theology, I argue that although the field of current disability theology has significantly developed in its ability to reflect the theological experiences and understandings of disability, it continues to show a strong inclination toward the social constructionist perspective and the identity model. This results, at best, in failing to understand mothers' complex and meaningful relationships with the medical model of disability and in disregarding the reality of mothers, especially the reasons they cannot dismiss the medical understanding of disability even when theologians have offered a theology of disability as an alternative.

The major source of conflict within the current psychosocial understanding of mothers of children with disability is over the narrative of parents/mothers. The dominant narrative of parents/mothers that was constructed by sociologists in the 1970s has criticized the constructionist perspective for its embedded medical perspective. Interestingly, the nature and object of the recent pushback observed in the psychosocial field is similar to what can be observed in disability theology: the medical model of disability has been, rightly, criticized for its less-humanistic and too-rigid structural perspectives.

In the third section on theological understandings of mothers of children, I argue that general theological studies as a field has paid less attention to the issues of and within families because it has instead focused on what has been considered grand issues. However, beginning in the late 20<sup>th</sup> century, a handful of theologians have noted the rising importance of and the need to connect the issues of disability and family.

The last section on “Hope” is to provide a theoretical framework to understand the psychospiritual well-being of the two research partners discussed in chapter 4 and the psychospiritual effect that different worldviews have on disability. I will introduce and discuss that topic in chapter 5.

Within this context, I argue that the theoretical framework I offer in Chapter 5 to understand mothers’ disability theology can: 1. Complement current disability theology, especially by strengthening its weakness in identifying and understanding the medical perspective of disability within mothers’ lived experiences and theologies; 2. Mediate the conflict over the construction of parents’/mothers’ narratives by providing an alternative framework within which to discuss and understand both sides; 3. Develop the theological

understanding of mothers' lived experience; and 4. Assist in the analysis of mothers' lived experience and of different worldviews on disability.

### **Disability Theology**

Disability theology as a field of study is "broad, ecumenical, and interdisciplinary."<sup>1</sup> John Swinton, in his review of that field, points out the variety of disciplines and perspectives on theological studies within various denominations in which disability theology has developed.<sup>2</sup>

What holds the area together as a united field are three shared characteristics. First, the subject matter of disability. To put it simply, the understanding of disability or the experience of disability is the subject matter for "theological reflection and practice."<sup>3</sup> Second, its main inquiries ask both What is the theological understanding of the existence and experience of disability? and How has disability been understood theologically? Theology pursues the fundamental theological meaning and value of disability or the human experience of disability so that ultimately it "enables church, academy, and society to live more closely with God's intentions."<sup>4</sup> The history of disability will set the backdrop to develop the framework of disability theology that I will offer in chapter 5 and also provides theological resources within which I interpret my research participants' lived theology. Finally, the third characteristic is the intention to advocate for people with disabilities as a way to fulfill the values of inclusivity. The first two elements are theological and the third, more pastoral. What can be inferred from this analysis of the theological study of disability is this: In theologians' aim to challenge, develop,

---

<sup>1</sup> John Swinton, "Disability, Ableism, and Disablism," in *The Wiley-Blackwell Companion to Practical Theology*, ed. Bonnie J. Miller-McLemore (Malden, MA: Blackwell, 2012), 443.

<sup>2</sup> Swinton, "Disability, Ableism, and Disablism," 443.

<sup>3</sup> Swinton, "Disability, Ableism, and Disablism," 443.

<sup>4</sup> Swinton, "Disability, Ableism, and Disablism," 444.

and revise the status quo, their “assumed norms and presuppositions (theological, cultural, and political)”<sup>5</sup> as well as their understanding of disability are based on clear “interpretations of scripture, tradition, and Christian practices.”<sup>6</sup> This context in which theologians have worked is an important area of consideration in this analysis. First-generation theologians of disability wielded their intentions with goodwill in employing the social model of disability when fighting toward a goal to achieve civil rights. In this case, they unfortunately overlooked the significance of other perspectives of disability—in this case, the medical understanding of disability. In the effort to create a new school of thought that was more inclusive, the desire to move away from the established medical understanding led to overlooking those medical ideas that should have been included. In other words, these theologians had to reject the medical understanding of disability wholly, rather than critically, not seeking to retain those elements that had value.

Hegel’s interpretation of history effectively serves to explore these dynamics in the history of disability theology. Hegel uses a dialectic method to understand the progress of history and philosophy. He postulates: “(1) a beginning proposition called a thesis, (2) a negation of that thesis called the antithesis, and (3) a synthesis whereby the two conflicting ideas are reconciled to form a new proposition.”<sup>7</sup> Hegel’s notion of a dialectical scheme can help identify the pattern developed in the field of disability theology because the development of disability theology shows similar dialectical patterns. It also helps us to see the intrinsic relationship of disability theology’s history; it is created and developed in connection with previous scholarly work, whether by following agreed-upon ideas or disagreeing with them. Within this analysis, the

---

<sup>5</sup> Swinton, “Disability, Ableism, and Disablism,” 444.

<sup>6</sup> Swinton, “Disability, Ableism, and Disablism,” 443.

<sup>7</sup> Sarah A. Schnitker and Robert A. Emmons, “Hegel’s Thesis-Antithesis-Synthesis Model,” in *Encyclopedia of Sciences and Religions*, ed. Anne L. C. Runehov and Lluís Oviedo (Berlin: Springer, 2013), [https://doi.org/10.1007/978-1-4020-8265-8\\_200183](https://doi.org/10.1007/978-1-4020-8265-8_200183).

context of disability theology's history is as significant as opposing views, given that antithetical views are only born from the existence of the original perspective. In turn, the synthesis of these opposing views is only granted holistic understanding through an exploration of the parts that form it. Interpreting disability theology with Hegel's dialectical scheme is important to my project, especially when it comes to chapter 5; that is because the framework that I propose in chapter 5 is intended to achieve this goal to synthesize previous theories on disability which are at the end of a polemic.

For this reason, I will explore the grand contour of the field through Hegel's philosophy of history. Disability theology was an unfamiliar term before 2000 in the field of Christian theology in the U.S.,<sup>8</sup> even as theologians were striving to understand disability in relation to Christian theology. Disability, both within and outside the church, has been associated with abnormality and in extreme cases closely connected to God's punishment, which reinforced the exclusion of people with disability from society. In addition, the legal rights of people with disabilities were not guaranteed. There was no legal protection from the discrimination they encountered in their daily lives.

In the context of disability, I see the thesis, "a beginning proposition," as a medical understanding of disability and what Swinton denotes as a Christian medical version of disability. This is a moral/religious understanding of disability in Reteo and Letšosa's categorization of models of disability. Swinton points out that these are essentially similar in that these perspectives locate disability in an individual's body and identify disability as a condition that requires external intervention to achieve internal change. It is under this condition that we can understand why first-generation theologians have collaborated with the social model of

---

<sup>8</sup> Erinn Stanley, "Intellectual Disability and Mystical Unknowing: Contemporary Insights from Medieval Sources," *Modern Theology* 28, no. 3 (July 2012): 385–401.

disability. Swinton also points out that this field of disability theology was born from its desire to challenge and revise “assumed norms of presuppositions (theological, cultural, and political)”<sup>9</sup> and – unlike traditional understandings – to bring positive reframing.<sup>10</sup>

Hence, in order to dismantle the established medical understanding of disability and its influence, the social model was one of the most prominent approaches that theologians used in their construction of disability theology. As we will see in chapter 5, the social model of disability was created exactly for this reason: to challenge the medical understanding of disability.

Interpreting from the Hegelian perspective, the goal of the first-generation theologians’ work was to negate the thesis, i.e., the medical model of disability. To revise the thesis, the first generation collaborated with the liberationist perspective of disability, another word for the social model of disability. There were various ways theologians worked to revise the presupposition of disability.<sup>11</sup> The most essential idea is in regard to the location of disability. First-generation theologians located disability outside of the individual in order to dismantle the prevalent idea that people with disabilities deserve discrimination because of the disability within their body. Now, the primary idea of first-generation theologians is that “Disability is a social experience that is shaped and formed by the particular context in which a person’s perceived difference is experienced. A person may have specific impairments (blindness, deafness, and so forth), but these need not be disabling. It is the negative reactions of society to these impairments that is disabling.”<sup>12</sup> In addition, one of the theologians’ most important goals in exploring disability is to provide a theological understanding that can counter this prevalent belief attached

---

<sup>9</sup> Swinton, “Disability, Ableism, and Disablism,” 443.

<sup>10</sup> Swinton, “Disability, Ableism, and Disablism,” 443.

<sup>11</sup> Swinton, “Disability, Ableism, and Disablism,” 443.

<sup>12</sup> Swinton, “Disability, Ableism, and Disablism,” 443.



to the notion of disability and to achieve civil rights. With this clear goal, the task of disability theology, then, is to critically reflect on the experience of disability/ability and examine theologically the causes of negative assumptions around the notion of disability.

### **Antithesis (1970–2000)**

This antithesis becomes the liberationist approach to disability theology, the theological work of the first-generation. Exemplary work was done by Nancy Eiesland, Kathy Black, and Jennie Block. While Eiesland's concern was inclusion of people with disabilities in society as well as in the church, Kathy Black's goal was to prevent people losing faith because of limited options in interpreting disability in the Christian tradition.

Nancy Eiesland, a person with a physical disability and a sociologist, has been actively involved in the disability rights movement, including her theological work *The Disabled God* (1994). Her main goal was to construct reliable theological symbols in Christianity that can enable people with disabilities to identify with a sound symbol of disability that normalizes the notion of disability to create a church community to which people with disabilities can belong comfortably. Perhaps because she has a sociological background, her perspective on disability was inclined to the social constructionist model of disability. It will be helpful if we can imagine the social context around the time the book *The Disabled God* was published in 1974. This was a time when the human rights of people with disabilities were not protected by law, and the disability rights movement began to achieve legal rights. The documentary "Crip Cramp"<sup>13</sup> illustrates this process. It shows how a summer camp for young people with disabilities fostered activism in 1971. I see a striking commonality between the main idea of Eiesland and the idea

---

<sup>13</sup> *Crip Camp*, directed by Nicole Newnham and Jim LeBrecht (Netflix, 2020), 1:46. <https://www.netflix.com/kr-en/title/81001496>.

promoted by the activists. Young people at Camp Joined in upstate New York collaborated with the idea and desired to “remove barriers that impinged on their path to independence.”<sup>14</sup> They saw that barriers that block their full presence in society were constructed in society; thus social activism was a logical step to take. This is the essence of the social model of disability, which was also employed by Eiesland in her analysis.

Eiesland, in order to analyze and critique how the church treats people with disabilities, began to examine society because she saw the history of the relationship between the church and the disabled is “at best ambiguous,” with the practices of the church strengthening “the societal structures and aptitudes that have treated people with disabilities as objects of pity and paternalism.”<sup>15</sup>

Eiesland uses the social model of disability in the process of deconstructing the accepted notion of disability. One understanding that was prevalent in early 1950, shortly after the two World Wars, was the vocational and medical rehabilitation understanding of disability. From this perspective, disability is equated in both medical and economic contexts to “a health-related limitation” and “inability to work.” In response to the medical and economic understandings of disability, a sociopolitical paradigm of disability emerged along with the civil rights movement, which later influenced the Americans with Disabilities Act (1990). This is called a minority model, which saw disability as a constructed notion that exists due to the way society and its institutions have been constructed, primarily focused on people without disabilities. These social contexts reinforced the disabled aspect of the identity and experience of people with disabilities.

---

<sup>14</sup> “Disability Rights Documentary ‘Crip Camp’ by Oakland Producers Up for Oscar,” ABC 7 NEWS, April 23, 2012, <https://abc7news.com/crip-camp-bay-area-oscar-nominations-disability-rights-documentary-san-francisco-1977-sit-in/10532748/>.

<sup>15</sup> Nancy L. Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville: Abingdon Press, 1994), 20.

What is Eiesland's understanding of disability? For Eiesland, disability is, first and foremost, a corporeal experience. It is important for her that people with disabilities express what they experience for themselves, which can disrupt the social norms and question the categories drawn for people with disabilities by those who do not know what it is like to live with disabilities. In this vein, Eiesland explicitly showed that when people with disabilities can speak their experiences it can reveal society's constructed nature of understanding disability, especially, then prevalent, as medical and economic.

Then, Eiesland, turns her attention to the Christian church. She asks, How have people with disability and disabilities themselves been understood in the church? For Eiesland, disability was something that blocks the full participation of people with disabilities in the church—either through the physical construction of the church or through the lack of Christian symbols that acknowledge and reflect disability. Eiesland diagnoses the church's practice as that of reinforcing society's prevalent attitude toward those with disabilities and thus begins her analysis with society. Eiesland points out that most churches were physically inaccessible to those with disabilities. She criticizes the lack of "theological interpretations of central Christian beliefs and practices" that could promote the full participation of people with disabilities and assure them of serious consideration as "historical actors and theological subjects."<sup>16</sup> Eiesland's proposal of the risen Jesus as the 'disabled God' was an attempt to create a reliable Christian identity for people with disabilities, one that can provide justification for their spaces and roles in the church so they can claim a right to have a seat in the church. For Eiesland, disability was part of God's image and God's experience, and it was thereby a rightfully normal Christian image

---

<sup>16</sup> Eiesland, *The Disabled God*, 20.

and experience of people of God. The risen Jesus is the ‘disabled God.’ Eiesland proposes an identity for people with disabilities, one with dignity that offers a representation of wholeness.

The most important contributions of Eiesland are, first, bringing the social model of disability into the Christian tradition, thereby showing that the tradition and practice of Christianity, like most religions, are not immune from the larger social context. Her work upholds an organic relationship between the church and society, in which the concerns and cares of the larger society directly influence and shape the lives of congregations. Second is in the ontological and spiritual power that the symbol of the disabled God brings to the theological table. This image became a religious metaphor that people with any kinds of disabilities can relate to and see themselves acknowledged and affirmed in their being with disability. The spiritual effect of this symbol is in providing a reevaluation of disabilities that will lead to the reevaluation of people with disabilities.

Eiesland’s work made implicitly clear that there are multiple ways of understanding disabilities—for example, medical and economic ways—although she discussed them to reject and criticize them. Eiesland argued that a minority model of disability emerged as a response to the medical and economic models. I agree with this, and I think more can be said about the dynamics that the minority model and medical/economic model create, which I show through mothers’ lived theologies in chapters 5 and 6. Although a minority model emerged and gained much power, it is difficult to say that the emergence of a minority model had a nullifying effect on other disability models. Medical and economic understandings of disability are still dominant, and they coexist to a large extent because of their undeniable influence in society and, to some extent, because of their, surprisingly, healing effects. Still, I do see that Eiesland’s focus on the social model and her rejection of the medical and economic models was inevitable and, to some

extent, necessary, given the context in which she lived. Basic and necessary social rights were not protected, and, in this situation, it is not only difficult to see and receive the benefits of the medical model that were not available then, such as the Social Security program that was established after the Americans with Disabilities Act of 1990, and support from communities and non-profit organizations. Moreover, from a strategic political perspective, considering where Eiesland stands historically, admitting the benefits or effectiveness of the medical model must have been a disadvantage in the effort to gain civil rights. It doesn't pragmatically help them to gain their human rights. In this vein, I see radical support of the social model of disability as a necessary historical step because the social model's contribution to legislation eventually enabled some medical services, Social Security benefits, and broader awareness of disability in the US. And even, I see as the historical process necessary toward my work: as I tried to synthesize these two opposing perspectives on disability through the framework that I offer in chapter 5.

While Eiesland, as a sociologist, began her analysis from society and narrowed it down specifically to the Christian church, Kathy Black (1996), as a professor of worship and preaching at Claremont School of Theology, began her analysis with the church. She observed that healing narratives, especially in a preaching context, often are mis-associated with the notion of disability or people with disabilities, which results in shunning people with disabilities. Thus, Black's goal was to deconstruct the meaning of "healing" and provide a theology that can both preserve the faith and offer a theologically sound understanding of disability.<sup>17</sup> Families of children with disabilities would ask: Why me? Why my child? Then, Black observes the way ministers answer was mostly limited to a traditional understanding of disability – that it is a

---

<sup>17</sup> Kathleen Black, *A Healing Homiletic: Preaching and Disability* (Nashville, TN: Abingdon Press, 1996), 10.

result of God's action in response to human behavior, whether as a sin or a blessing. Black found out that these answers were closely related to theodicy. Thus, Black situates the discussion of disability in the theological locus of theodicy. Questions of theodicy seek answers about God's will, especially in any humanly unbearable situation. In this context, the question is whether it is God's will for someone to have a disability. One of the important points that underlies theodicy is the existential question of whether people with disabilities are or are not accepted by God. Black saw that many people in ministerial positions do not know how to respond to people with disabilities. Black said,

One problematic message many churches convey is that persons with disabilities are both blessed by God and cursed by God. Some within the Christian tradition label the persons with a disability as 'angels' while others label the same persons as 'devils.'<sup>18</sup>

These images, whether angel or devil, each dehumanize a person with disability. The parallel phenomenon in the secular world is seeing people with disabilities and their efforts to "achieve" the unachievable as inspirational models.

As an alternative, Black proposes a theology of interdependency that redefines the meaning of an all-powerful God. Instead of believing in an all-powerful God who is responsible for everything that happens in our lives, including disabilities. She makes her point clear that disability is not an intention of God. If so, then where is God in the reality and experience of disability? What is God's role in making us deal with disability? Black says God is present in the midst of suffering. Black's answer to the question of what disability means theologically, is in line with what we saw in Eiesland's construction of the disabled God in that it directs our attention to the ontological meaning of disabilities and people with disabilities while resolving the problematic association of disability and God in relation to theodicy. God is not the cause of

---

<sup>18</sup> Black, *A Healing Homiletic*, 15.

disability, but God is with those people with disabilities. Here, note that Black qualifies the notion that necessarily equates suffering with disabilities and says that there are also groups of people with disabilities who do not perceive themselves as suffering. Resurrection, or God's action, is represented as inclusion into a community. That is healing for Kathy Black: being fully integrated into the community.<sup>19</sup> I will look more closely into community in the following section: Interdependency as a way of life and theological norm. In Black's theology of disability, God is not the cause of suffering.

A theology of interdependency is, however, not without limits. Black equates, with good intention, the experiences of people with disabilities, suffering, and God's presence in her theological proposal. Thus, she makes a note that not all people with disabilities have painful experiences of exclusion. Still, those experiences are presented as one-dimensional. Furthermore, questions follow when it comes to practicing the inclusion of people with disabilities. For example, how does the inclusion of people with disabilities exactly become restorative? What exactly does it mean to be in community? In order for a person to feel that she belongs in the community, to what extent does a person need to be involved? How could an asymmetric power dynamic between people with disabilities and people without disabilities be addressed, understood, and, if needed, become reconciled? Lastly, Black said that people with disabilities deserve the same amount of care from the church and community as people who are not disabled.<sup>20</sup> Who, then, will take this role? These questions need to be answered.

Jennie Block's theological interpretation of disability is also included in the category of antithesis stage of theological constructions of disability. Like Eiesland and Black, Block's goal was to promote inclusion of people with disabilities. With this specific goal, the notion of

---

<sup>19</sup> Black, *A Healing Homiletic*, 49.

<sup>20</sup> Black, *A Healing Homiletic*, 30–31.

“access and inclusion” becomes the major theological concept that functions as a lens through which to examine the image of God.<sup>21</sup> That means that the lens of disability emphasizes the character of God who “is unfailingly committed to inclusion and access.”<sup>22</sup> The prime example is Jesus, who practices indiscriminate hospitality. Creamer explains Block’s theology,

This, she says, was the message of Jesus: all are welcome, and all have a place. According to Block, the New Testament account shows that Jesus included all people in his ministry, regardless of nationality, gender, background, or physical condition.<sup>23</sup>

Through this account, Block “highlights disability as an issue of oppressive structures and exclusion. Because of this, the accessible God not only offers us images of inclusion but also calls for an end to oppressive structures.”<sup>24</sup> This is how, for Block, “disability is related to ‘the mystery of God’s love and the great paradoxes of the Christian message.’”<sup>25</sup>

These theologians, Nancy Eiesland, Kathy Black, and Jennie Block, commonly emphasize the ontological and theological value of disabilities with their very specific goal to reevaluate and reinterpret the experience of disability and the people with disabilities in a positive light. Their common goal in doing so was clearly to include people with disabilities in the Christian community as well as the broader society. Each theologian calls us to see the notion of disability by looking at the larger context of society and church. This encourages us to change our perspective in looking at disability beyond its prevalent negative stigma. For these theologians, the experience of disability only underscores God’s presence in the lives of people with disabilities. They have found the place of God in the experience of people with disabilities.

---

<sup>21</sup> Deborah Creamer, “Theological Accessibility: The Contribution of Disability,” *Disability Studies Quarterly* 26, no. 4 (Fall 2006): 5, <https://dsq-sds.org/article/view/812/987>.

<sup>22</sup> Creamer writes, “While God cannot be fully known, she [Block] argues that the lens of disability highlights a God who is unfailingly committed to inclusion and access.” Creamer, “Theological Accessibility,” 5.

<sup>23</sup> Creamer, “Theological Accessibility,” 5.

<sup>24</sup> Creamer, “Theological Accessibility,” 5.

<sup>25</sup> Jennie Block, *Copious Hosting: A Theology of Access for People with Disabilities* (New York: Continuum, 2002), 22, quoted in Creamer, “Theological Accessibility,” 5.



Interestingly, while doing so, what these theologians have done is to move away from the traditional understanding of God as a transcendent and omnipotent being. For instance, Eiesland introduces us to God who is disabled; for Black, God couldn't be omnipotent, as God is not responsible for anyone's disability. Block sheds light on the aspect of God whose priority is placed on access and inclusion. Furthermore, what underlies these theologies is the notion that 'God is with those who are disabled' and that Christian community becomes the vessel that represents God's presence. In this perspective, their theologies promote affirmation of those people with disabilities and promote an understanding of disabilities, by causing a similar effect with the affirmation model in Retief's categorization. I agree and conceive these ideas as a powerful contribution to the field of theology and the practice of ministry.

There are several limits of these theologies. First, theology aligning with the social model results in several shortcoming. This liberationist approach highlights the experience of marginalization, yet ironically excludes those who do not share the experience. Second, highlighting the liberationist approach develops the tension among various models of disability. For example, as Eiesland said, the social model was born and has grown in an effort to resist the medical and economic models of disability prevalent in sociological analysis. Eiesland brought exactly this resistance framework into the field of theology, resulting in, as I see it, successful deconstruction of the dominant theological notion of disability and reconstruction in more life-giving ways. Eiesland's framework has shaped the entire field of disability theology, in that this conflict between social-and-identity and medical-and-economic models continues. This polarization within disability theology leads to the lost opportunity to carefully explore theological or psychological ramifications of the medical and economic models of disability. The unintended result of these kinds of theological constructions was to strengthen the trend of

theological studies to perceive the medical understanding of disability as a thought to be opposed, allowing scholars too easily to overlook positive or useful aspects of the medical perspective. In the next stage of scholarship, synthesis, we see the beginning of movement from theologians as they attempt to strike a balance between the medical understanding of disability and the social model.

### **Synthesis (from the Year 2000)**

Second-generation theologians have begun what I see as the task of synthesis by moving the pendulum of scholarship away from a liberationist stance closer to the medical and economic models. What takes place in this stage is literally synthesizing the conflicting ideas of thesis and antithesis: the medical understanding and moral/religious understanding vs. the social model of disability.

To understand this shift, it is important to note the contemporary political scene in the United States. The Americans with Disabilities Act (ADA) was signed into law on July 26, 1990, by President George H.W. Bush. This came as a result of years of effort by American citizens, with and without disabilities, arguing for legislation that protected the basic human and civil rights of those with disabilities. The ADA is the “most comprehensive civil rights legislation that prohibits discrimination and guarantees that people with disabilities have the same opportunities”<sup>26</sup> “in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public.”<sup>27</sup>

---

<sup>26</sup> “Introduction to the Americans with Disabilities Act,” ADA.gov: U.S. Department of Justice Civil Rights, <https://www.ada.gov/topics/intro-to-ada/>.

<sup>27</sup> “What Is the Americans with Disabilities Act (ADA)?” ADA National Network, December 2022, <https://adata.org/learn-about-ada>.

The political movement that resulted in the ADA is not unrelated to theological developments related to disabilities. The liberationist approach achieved its goal by securing through legislation the rights of people with disabilities. But now the liberationist strategy is more or less obsolete; the enactment of the ADA, by satisfying the pragmatism of the liberationist view, forced theologians to consider the experience of disability in a different, more flexible light. Now that social, political, and theological contexts for people with disabilities were changed for the better, the adversarial stance theologians once took toward the medical understanding of disability was less warranted. The legal rights and livelihoods of the disabled were protected and secured, but stigmas toward disability and mental illness remained. The discriminatory attitudes toward those deemed as ‘others’ and the experience of being excluded became the primary concern of theologians and advocates. Hence, after the year 2000, theologians have taken a slightly different approach than that used by earlier theologians to an understanding of the topics of disability and theology.

While most of the work of first-generation disability theologians had focused on providing ontological theological understandings that use the social model to displace the idea that disabilities are located in the individual, second-generation theologians employ a more balanced perspective by incorporating the medical understanding of disability. They begin to take a stance that is not necessarily negative toward or exclusive to the medical understanding of disability. This more integrative and broader perspective has the capacity to embrace notions generally considered to be dichotomic such as healthy and unhealthy, abled and disabled, etc. For instance, health no longer meant ‘a physical or mental state of a person absent of disability or illness;’ rather, health depended on what kinds of relationships a person develops with the disability. In the discussions of first-generation theologians, disability and ability stood at either

end of a continuum, but now these poles are integrated instead of being deemed as mutually exclusive. Still, this does not mean these thinkers abandon the social model; they use it in a way that is more inclusive of the medical understanding. Exemplary works are by John Swinton (2000), Kathleen Greider (2007), and Amos Yong (2007).

John Swinton, a practical theologian, who was also once a nurse practitioner and a chaplain, said that the foundation of much of his research and teaching has emerged from his background in nursing, ministry and healthcare chaplaincy. A part of his project to offer a normative understanding of care relationships for people with mental illness provides a framework to embrace the experience of disability. It begins with of human life. In this regard, health is understood as the relational framework within which to understand a human person in her interactions with illness. Thus, health is not an ideal state; rather it is the strength to live and to cope, including with illness.

Second, Swinton guides us to see a person irrespective of circumstance. In *Resurrecting the Person*, Swinton is clearly aware of the danger of a person becoming totally identified with a personal mental-health problem.<sup>28</sup> For instance, according to Swinton, clinical identities become social identities such as “schizophrenic,” “dementia victim,” “manic-depressive,” blocking “the opportunities to develop healing relationships with God, self, and others.”<sup>29</sup> These ways of identification are often blurred with a person’s entire identification. So Swinton, as part of “resurrecting persons,”<sup>30</sup> is attempting “to separate the person from the illness.”<sup>31</sup> Using Keith Todor’s idea, Swinton proposes a way to see a person along two continua; one is mental health,

---

<sup>28</sup> John Swinton, *Resurrecting the Person: Friendship and the Care of People with Severe Mental Health Problems* (Nashville, TN: Abingdon Press, 2000), 133.

<sup>29</sup> Swinton, *Resurrecting the Person*, 133.

<sup>30</sup> Swinton, *Resurrecting the Person*, 134.

<sup>31</sup> Swinton, *Resurrecting the Person*, 134.

the other is a 'ill health.'<sup>32</sup> This model is a distinctive one. In the ill-health model, the primary focus will be on illness as the traditional psychiatric, biomedical world conceives it. In the health model, the focus will be on “meaningful personal relationships, spiritual direction, the quest for meaning, a valued place within society and so forth.”<sup>33</sup> Another way, suggested by John Strauss, is to think of “a person who has a disorder, rather than a person who is a disorder.”<sup>34</sup> This distinction empowers a person who experiences a mental-health problem not to accept it as a complete identity, giving the affected person the freedom to remain a person distinguished from the mental-health problem. Next, I will explore Kathleen Greider’s work.

Kathleen Greider, in her work *Much Madness Is Divinest Sense*, demonstrates the complex realities of the experience of mental illness by exploring a variety of memoirs using autobiographical data, mostly published books and articles, by people with first-person experience with mental illness. From it, Greider proposes spiritual insights and values drawn from the experiences of those who suffer soul-sickness, in other words, a mental illness, and those who care for people with mental illness. What is outstanding in her work in addition to thick description and her analysis, is the epilogue, the way she draws spiritual and pastoral insights from the lived experience by not taking a side against traditional dichotomic thinking. For example, as we saw, the first-generation theologians worked against the medical understanding of disability to argue that the illness is defined by outside factors but is not essentially a negative thing. This was done in order to mitigate the detrimental influence of the medical perspective – although the stigma, especially toward mental illness, still exists. The traditional dichotomic dynamic of health and illness is no longer continued in Greider’s work.

---

<sup>32</sup> Swinton, *Resurrecting the Person*, 134–44.

<sup>33</sup> Swinton, *Resurrecting the Person*, 134.

<sup>34</sup> Swinton, *Resurrecting the Person*, 137.

I position Greider in the category of synthesis because of this balance she achieves. A prime example is when Greider guides us to understand the value of both health and its limits.

First, Greider provides the value of health:

Health is a core value of human life that we mature those abilities ...for the sheer delight of a task well done, when exercised, they make it possible for us to take responsibility for the material support of our own lives and to make a contribution to the common good.<sup>35</sup>

The meaning imbued in health here aligns with the value promoted by the medical understanding. While recognizing the strength/benefits of the medical understanding of disability, Greider doesn't take a position that accepts only the medical understanding of health. Greider moves always from the medical understanding when she embraces the human experience of limits, unlike the medical understanding of disability that promotes only health but negatively deems functional limits, disease, and illness. Greider takes up these experiences of limits and failures of abilities and shows that these are not just negative experiences. For example, from several memoirs, Greider notes that those who experienced significant limits in their health, or those whose intimate others experience limits, found a source of relief in many ways. For instance, valuing the experience of limits brings more:

It can give us rest from the relentless pursuit of being in some condition other than where we are. It can make it safer to be honest. It can foster an atmosphere characterized as much by relaxed humility as by hard-nosed competence. Instead of always working to develop our abilities, engaging our limits invites us to play more often. Engaging our limits encourages interdependence as much as self-reliance and expands our attention beyond our own abilities toward powers beyond ourselves.<sup>36</sup>

---

<sup>35</sup> Kathleen J. Greider, *Much Madness Is Divinest Sense: Wisdom in Memoirs of Soul-Suffering* (Cleveland, OH: Pilgrim Press, 2007), 308.

<sup>36</sup> Greider, *Much Madness Is Divinest Sense*, 312.

The experiences of limits and failures can become opportunities for people, especially those who have lived their lives from a success-oriented and ability-driven perspective, to pause and reflect on the values they have pursued. They will soon realize that their previous success- or ability-driven perspectives are no longer adequate for their own experiences of limits and failures. Experiences of limits and failures reveal the cracks in the values and perspectives they held earlier, and that awareness gives them a chance to rebuild them to make sense of their own experiences. Greider highlights parents who have transformed their perspectives so that they were able to embrace their loved one's experiences over their own previously held beliefs. This brings about "the start of a new life," "to begin to set new horizons within what was possible, and to value those more limited possibilities."<sup>37</sup>

As such, Greider guides us to see spiritual insights in dichotomy. Here we need sensitivity. The intention is certainly not to give equal value to both health and infirmity as Greider repeatedly cautions us. She understands the reality of illness, its everyday tolls and difficulties; however, there may be something to learn from it regarding how most people think about health and illness. What I see as one of Greider's most important contributions occurs when she carefully asks us where, in either state, we can find 'grace'—that grace can exist in health and illness. It is important to note that by putting these seemingly opposite concepts together, Greider repeatedly cautions readers that it is important not to minimize the devastation of the challenges or the reality of soul-sickness, nor to romanticize either one. One of the important goals, for Greider, is to show the most possible real experience of the struggle. Swinton and Greider both posit frameworks that have the effect of diluting both the positive and

---

<sup>37</sup> Greider, *Much Madness Is Divinest Sense*, 310.

negative value imbedded in ideas about illness and provide a perspective to see the experience of illness as a ‘human phenomenon.’

Lastly, Amos Yong’s theological construction of disability, which also aimed to balance the medical and social models of disability. In his *Theology and Down Syndrome: Reimagining Disability in Late Modernity*,<sup>38</sup> Yong describes his goal “to articulate a more inclusive view of what it means to be human, a more hospitable image of the church, a more holistic understanding of divine salvation, and a more expansive image of God’s eschatological hospitality.”<sup>39</sup> To this end, Yong employs the ‘pneumatological imagination.’ (‘Pneuma’ means spirit in Greek.) Coming from the Pentecostal tradition of Christianity, and based on Acts 2 of the New Testament, Yong utilized the metaphor of the ‘many tongues’ of Pentecost, adopting the theological concept of the Holy Spirit allowing diverse languages as a blessing. This becomes fundamental to Yong’s theology in that it gathers “the narratives of people with disabilities and the many professional, scholarly, and scientific discourses that illuminate the experience of disability.”<sup>40</sup>

Just as many tongues are a sign of blessing from God, human differences embodied in the differences and otherness of disability are a sign of blessing. That is, Yong’s pneumatological imagination “provides a theological rationale for preserving the integrity of difference and otherness, but not at the expense of engagement and understanding. Finally, it alerts and invites us to listen to the plurality of discourses and languages in the hope that even through ‘strange tongues,’ the voice of the Holy Spirit may still speak and communicate.”<sup>41</sup>

---

<sup>38</sup> Amos Yong, *Theology and Down Syndrome: Reimagining Disability in Late Modernity* (Waco, TX: Baylor University Press, 2007).

<sup>39</sup> Yong, *Theology and Down Syndrome*, 292.

<sup>40</sup> Yong, *Theology and Down Syndrome*, 14.

<sup>41</sup> Yong, *Theology and Down Syndrome*, 11–12.



This includes the perspective of biomedicine. “Yong proposes instead a perhaps too easy ‘both/and’ approach to the conflict: disability is both a positive biomedical condition and a constructed social condition.”<sup>42</sup> Yong’s attempt to move beyond this dichotomic relation is a continuation of his attempt to overcome “us/them or nondisabled/disabled dichotomies,”<sup>43</sup> which can easily be found in our day-to-day lives. Through his both/and approach Yong helps people to accept the medical perspective and not to take a stance against it.

In the understandings of disability proposed by John Swinton, Kathleen Greider, and Amos Yong we see a more accepting stance toward the medical worldview of disability, than the way first-generation theologians treat the medical worldview. This theological framework allows us to accept illness as part of human experience. We can also find that unlike the first stage of the theological literature, antithesis, in the synthesis stage, human agency emerged as important. For example, in the first stage because theological understanding is inclined to the social model, disability is located in the social context. Naturally, there is very little room for human activity other than participating in a social activist movement. While mention of the importance of social activism is unnecessary, the reality is there are fewer resources – spiritual, psychological, and theological – that can be used on an individual level. In the stage of synthesis, however, the power to interpret the experience of ability and disability to some extent depends on the individual. Most importantly Greider and Yong especially demonstrate what I aim to develop through this project, that the breadth and depth of theological understandings of disability are greater than the medical perspective; we don’t need to oppose it.

---

<sup>42</sup> Rosalynde Welch, review of *Theology and Down Syndrome: Reimagining Disability in Late Modernity* by Amos Yong, *Brigham Young University Studies* 48, no. 2 (2009), 187–91.

<sup>43</sup> Welch, review of *Theology and Down Syndrome*, 187.

Within this context, I situate my work, especially chapter 5, as part of the strand of synthesis, alongside second-generation theologians, because I pay close attention to the positive and beneficial functions of the medical understanding of disability, especially its psychological and communal functions a significant limit of liberationist-focused disability theologians. The functions of theological ideas regarding disability that current theological literature has missed and what I am trying to uphold can be explained by practical theological hermeneutics and the communal-contextual paradigm of pastoral theology. While doing so, I will illustrate the value of practical and pastoral theological exploration that incorporates psychology and communal-contextual analysis. For now, I will turn to the psychosocial understanding of parents of children with disabilities.

### **Psychosocial Understanding of Parents Who Have Children with Disabilities**

The experiences of parents of children with disabilities have been explored primarily in a variety of fields such as counseling, sociology, medical anthropology, and occupational therapy. There are three broad strains of research on the experience of parents. 1. experience of parenting children with disabilities stressful and rewarding because of personal growth, 2. psychoanalytic perspective of what mothers experience in their emotion (affect) and 3. describing parents' experiences in a process through narrative.

### **Challenges and Rewards of Raising Children with Disabilities**

Psychosocial literature has generally agreed that raising children with disabilities is much more challenging and difficult than raising a non-disabled child. However, there is a tension in

deciding what specifically causes a mother's difficulties and how those difficulties are experienced by individual mothers.

Two approaches to research stand out about the stress parents experience. Research from the mid-20th century has consistently demonstrated and emphasized the difficulties and stress these parents' experience.<sup>44</sup> Before going further, let me introduce the definition of stress. According to a group of neuroscientists who wrote the article, "Stress revisited: A critical evaluation of the stress concept," "the term 'stress' should be restricted to conditions where an environmental demand exceeds the natural regulatory capacity of an organism, in particular situations that include unpredictability and uncontrollability."<sup>45</sup> This provides a clearer lens to understand parents' situations: They are mostly placed in a situation where the resources they can offer in caring for their children with disabilities is more limited than the kinds of demands they face in a number of different ways.

The challenges range from emotional and economic difficulties related to caring for their children, to discrimination faced within the educational system, referred to as public rejection, both in institutional systems and in "personal interactions."<sup>46</sup> These challenges result in parents' stress, both physical and psychological.<sup>47</sup> Lack of support, both individual and systemic, can cause two phenomena. First, families may, to some extent, be forced to provide or come up with their own way to care for their children with disabilities. In this context, "Families are a critical

---

<sup>44</sup> Priya Lalvani and Lauren Polvere, "Historical Perspectives on Studying Families of Children with Disabilities: A Case for Critical Research," *Disability Studies Quarterly* 33, no. 3 (2013), <https://dsq-sds.org/article/view/3209/3291>.

<sup>45</sup> J. M. Koolhaas et al., "Stress Revisited: A Critical Evaluation of the Stress Concept," *Neuroscience & Biobehavioral Reviews* 35, no. 5 (2011): 1291–301, <https://www.sciencedirect.com/science/article/abs/pii/S0149763411000224?via%3Dihub>.

<sup>46</sup> Lucie P. Lawrence, "Hardly a Walk in the Park: Examining Disability through a Mother's Eyes," *Journal of Loss and Trauma*, 13, no. 6 (2008): 528–40.

<sup>47</sup> Taylor N. Downey, "Children with Special Needs and the Effect on the Family" (master's thesis, Eastern Illinois University, 2016), 7.

source of support for children with disabilities. Family members absorb the added demands on time, emotional resources, and financial resources.”<sup>48</sup> John D. McLennand et al point out that “when there are high stress levels involved, it can lead to an increased use of undesirable parenting strategies, suppressing and voicing problems, as well as lower social skills developed by the children.”<sup>49</sup> According to Bower and Hayes “a high level of stress and exhaustion comes with mothering a child with an intellectual and physical disability.”<sup>50</sup>

Second, this situation wherein the family becomes a major source of support for their children with disabilities puts many of those families in vulnerable positions economically and socially. Research shows that the magnitude of financial and psychological stress was twice for parents raising children with disabilities compared to parents of children with no disability.<sup>51</sup> In this situation, Clare Harvey points out that as “parents of non-disabled children are not culturally sanctioned to admit the burden of childrearing, and that is even more the case for parents of disabled children.”<sup>52</sup>

### Mothers’ Emotional Experience from a Psychoanalytic Perspective

Clare Harvey’s article on “Maternal subjectivity in mothering a child with a disability: A psychoanalytical perspective” provides important insights on mothers’ emotional experiences and offers a literature review from a psychoanalytic perspective. As Harvey used the term ‘Maternal ambivalence: ‘Eternal and natural,’ I also think the notion of ambivalence adequately

---

<sup>48</sup> Susan L. Neely-Barnes, “Families of Children with Disabilities: A Review of Literature and Recommendations for Interventions,” *Journal of Early and Intensive Behavior Intervention* 5, no. 3 (2008): 93–107.

<sup>49</sup> Neely-Barnes, “Families of Children with Disabilities,” 93–107.

<sup>50</sup> Clare Harvey, “Maternal Subjectivity in Mothering a Child with a Disability: A Psychoanalytical Perspective,” *Agenda: Empowering Women for Gender Equity* 29, no. 2 (2015): 89–100.

<sup>51</sup> Anthony Goudie, Marie-Rachele Narcisse, David E. Hall, and Dennis Z. Kuo, “Financial and Psychological Stressors Associated with Caring for Children with Disability,” *Family System Health* 32, no. 3 (2014): 280–90, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4315505/>, accessed June 20, 2022.

<sup>52</sup> Harvey, “Maternal Subjectivity,” 96.

captures the complexity of mothers' experiences. Harvey begins by explaining that mothers, even when they have non-disabled children, experience a sense of ambivalence. By quoting scholars who have pointed out these mixed feelings of mothers such as Winnicott, Parker, Raphael-Leff and more, Harvey shows that mothers' experience of ambivalence is indeed a natural phenomenon. For example, Winnicott remarks on the inevitable feeling of hate that mothers experience. "The most remarkable thing about a mother is her ability to be hurt so much by her baby and to hate so much without paying the child out, and her ability to wait for rewards that may or may not come."<sup>53</sup> Parker pointed out similarly that mothers feel both love and hate toward their children and express this as "the unacceptable face."<sup>54</sup> More recently Raphael-Leff points out that this experience of hatred is one of the painful maternal emotions that is under-researched.<sup>55</sup>

Then, Harvey continues to point out that while the experience of ambivalence of mothers of non-disabled children has not been directly applied to mothers of children with disabilities through research, the ambivalence of mothers of non-disabled children are pertinent to mothers of children with disabilities as their love, hate, and expectation are only heightened.<sup>56</sup> For example, Sadat Nurullah's research points out the highs and lows generated by caring for children with disabilities.<sup>57</sup> For instance,

Joyful feelings as well as stress, burden, sorrow and mental exhaustion were reported. Parents described feelings of self-blame, as well as being judged by society, which left them feeling overwhelmed and rejected. . . . Further, mixed feelings of concern as well as hope for their child's future were reported.<sup>58</sup>

---

<sup>53</sup> D. W. Winnicott, "Hate in the Countertransference," *International Journal of Psychoanalysis* (1949): 356, quoted in Harvey, "Maternal Subjectivity," 94.

<sup>54</sup> Rozsika Parker, *Torn in Two: The Experience of Maternal Ambivalence* (London: Virago, 1996), 49, quoted in Harvey, "Maternal Subjectivity," 95.

<sup>55</sup> Joan Raphael-Leff, "Healthy Maternal Ambivalence," *Psycho-Analytic Psychotherapy in South Africa* 18, no. 2 (2010), quoted in Harvey, "Maternal Subjectivity," 94.

<sup>56</sup> Harvey, "Maternal Subjectivity," 95.

<sup>57</sup> Harvey, "Maternal Subjectivity," 96.

<sup>58</sup> Harvey, "Maternal Subjectivity," 96–97.

Mothers also felt “anger and a sense of unfairness that this was not the child they had expected” according to Ryan and Runswick-Cole’s research.<sup>59</sup> Bosteels et al uses the expression of ‘riding a roller coaster’ to describe parenting a deaf child, “with many ups and downs leaving parents feeling confused and overwhelmed.” Parts of the fear and doubt are resulted from not knowing what to do as a new parent of children with disabilities and from being overwhelmed by medical advice and procedures.<sup>60</sup> Harvey points out this complex psychological experience can increase the sense of inadequacy and can be directed toward their children, self, partner and society.<sup>61</sup>

There is another line of research that is significant to understand mothers’ experience discussed by Clare Harvey. Studies point out that the topic of disability to non-disabled people is “highly complex and often contradictory, causing many individuals to be both fascinated and repelled”<sup>62</sup> with a sense of anxiety.<sup>63</sup> This psychological phenomenon can be explained by ‘projection.’ Projection is,

A psychoanalytical term to describe the psychological defense of unconsciously disowning difficult feelings and experiences by ‘putting’ these into other people, which are then identified as being part of that other person. In this way these parts no longer belong to one’s self.<sup>64</sup>

That is, the reason why disability becomes such an uncomfortable topic can be due to non-disabled people’s feeling of anxiety caused by seeing people with disabilities’ aspect of vulnerability and dependency.<sup>65</sup> For instance, Shakespeare coins the term ‘dustbins for disavowal’ to describe people with disabilities “as non-disabled people ‘throw’ and project their

---

<sup>59</sup> Harvey, “Maternal Subjectivity,” 97.

<sup>60</sup> Harvey, “Maternal Subjectivity,” 97.

<sup>61</sup> Harvey, “Maternal Subjectivity,” 97.

<sup>62</sup> Harvey, “Maternal Subjectivity,” 92.

<sup>63</sup> Harvey, “Maternal Subjectivity,” 92.

<sup>64</sup> Harvey, “Maternal Subjectivity,” 92.

<sup>65</sup> Harvey, “Maternal Subjectivity,” 92.

unwanted psychological characteristics onto disabled people.”<sup>66</sup> Harvey added that this can affect the way non-disabled people respond to people with disabilities.<sup>67</sup> This projection also takes place when non-disabled mothers have children with disabilities.

When mothers project their negative emotions onto their children with disabilities “disabled children might become unconsciously attached to their mothers’ unbearable and difficult emotional aspects.”<sup>68</sup>

### The Construction of a Dominant Narrative and Movement of Deconstruction

Beginning in the 1970s, there has been a scholarly effort to understand and affirm the experiences of parents who are raising children with disabilities. In her book *Families Against Society: Reactions to Birth Defects* (1979), Rosalyn Darling, a sociologist, drew a blueprint of this in a narrative form, which afterward became the dominant narrative representing parents’ experience.<sup>69</sup> In it, Darling identifies common responses and experiential patterns of action of parents of children with different disabilities. In Stanley Hauerwas’ words, “Darling’s book is primarily an account of how parents were taught by their handicapped children to be parents.”<sup>70</sup> Darling describes what parents undergo in a number of stages, beginning with the birth of their child.<sup>71</sup> She describes the experience as a movement “from anomic to activism.”<sup>72</sup> Darling

---

<sup>66</sup> Harvey, “Maternal Subjectivity,” 92.

<sup>67</sup> Harvey, “Maternal Subjectivity,” 92.

<sup>68</sup> Harvey, “Maternal Subjectivity,” 92.

<sup>69</sup> Darling’s participants were twenty-five parents who were randomly selected from the files of a university genetics counseling service. Interviews with parents and their pediatricians were conducted, and each parent filled out a self-report document.

<sup>70</sup> Stanley Hauerwas, “The Retarded, Society, and the Family: The Dilemma of Care,” in *Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped, and the Church* (London: Continuum International Publishing, 1986), 167.

<sup>71</sup> Darling divides the experience into eight topics: background information, prenatal knowledge, attitudes and experiences, birth, infancy, early childhood, later childhood and adolescence, and expectations for the future. Darling, *Families against Society: Reactions to Birth Defects*.

<sup>72</sup> Hauerwas, “The Retarded, Society, and the Family,” 167.

named the first stage “anomic” to show “the parents’ feelings of helplessness and lack of support in the face of what appears at the time to be an overwhelming tragedy.”<sup>73</sup> In the “seekership” phase, parents attempt to find information about their child and how to cure this child’s disability. After this stage, the parents’ hopes for miracles or cures begin to disappear. It is at this point that parent realize they can accept (that is, to think it possible for) their children to be disabled. Then, parents enter the “advocacy” phase to create circumstances that provide better care for their child. Darling’s narrative became dominant in academic disciplines ranging from medicine and sociopsychology to theology, given the number of cases where scholars quote and use Darling’s theory to understand parents’ experiences. In theology, Darling’s narrative was used by Stanley Hauerwas to provide a theo-ethical understanding of parents of children with disabilities.<sup>74</sup>

After the year 2000, this dominant narrative encountered a noticeable backlash. Scholars began to raise questions and found that while the dominant narrative has provided the framework within which to understand parents’ experiences, it also functioned to reinforce stereotypes of parents. That resulted in the consensus that the dominant narrative was insufficient to account for the detailed nuances of parents’ experiences.

Jay A. Goddard, Ron Lehr and Judith C. Kapadat, for example, in their article “Parents of Children with Disabilities: Telling a Different Story,” undertake a qualitative research study using a narrative therapy approach to see to what degree parental experiences converge with or diverge from the dominant narrative.

---

<sup>73</sup> Hauerwas, “The Retarded, Society, and the Family,” 167.

<sup>74</sup> Hauerwas, “The Retarded, Society, and the Family,” 160–69.



One of the points of divergence was the assumptions made in regard to being the parent of a child with disability.<sup>75</sup> For instance, parents reported that they have had experiences with medical professionals who have “horrible pictures and stereotypes” or “tragic and dysfunctional” understandings of disability, especially in the early stages of learning to understand their child’s disability.<sup>76</sup> The medical professionals think that being a parent of a child with disabilities is one of life’s most difficult and terrible challenges.

The study found that “these negative views often contrasted with parents’ lived experiences.”<sup>77</sup> First, the dominant narrative neglects other ways to respond. The dominant narrative identifies sadness and a sense of guilt as the primary emotional experiences of parents. What is notable from this study was that some parents were responding and reacting with laughter and humor when they have come to terms with their children’s disabilities and when they have dealt with and moved beyond sadness and guilt. Unlike the dominant discourse, some parents related their experiences with optimism and humor “as important antidotes for sadness and guilt.”<sup>78</sup> For example, following a conversation that took place in a parent support group, the narrative below demonstrates how parents use humor to make sense of their situation.<sup>79</sup>

Mary: I was looking for weeping and whining. (Laughter)

Nancy: So was I and there was none—not even five minutes. I thought we were supposed to have a glass of wine, all break down and get this out and—nothing. They made rude comments and smart remarks. (Laughter)

Mary: I thought, ‘Who are these people?’

Karen: But you kept coming. You persevered.<sup>80</sup>

---

<sup>75</sup> Jay A. Goddard, Ron Lehr, and Judith C. Lapadat, “Parents of Children with Disabilities: Telling a Different Story,” *Canadian Journal of Counselling* 34, no. 4 (2000): 278.

<sup>76</sup> Goddard, Lehr, and Lapadat, “Parents of Children with Disabilities,” 278.

<sup>77</sup> Goddard, Lehr, and Lapadat, “Parents of Children with Disabilities,” 278–79.

<sup>78</sup> Goddard, Lehr, and Lapadat, “Parents of Children with Disabilities,” 281.

<sup>79</sup> The authors note, “In recent years, a strong sense of humour has emerged in the disabled activist movement.” Goddard, Lehr, and Lapadat, “Parents of Children with Disabilities,” 281.

<sup>80</sup> Goddard, Lehr, and Lapadat, “Parents of Children with Disabilities,” 281.

This episode reveals, as Jay A. Goddard, Ron Lehr and Judith C. Kapadat argue, that “perspectives like chronic sorrow are stereotyping in that they fail to recognize that having a child with a disability includes laughter along with the tears.”<sup>81</sup>

Second, the descriptions of parents drawn in the dominant narrative functioned as the standard for being a good parent. For example, some parents reported that they have experienced being judged by others to be in a state of denial, having unrealistic expectations, and being “more prone to abuse their children.”<sup>82</sup> The framework of ‘parents being an advocate’ was also reported to have negative effects on parents, because then parents felt that they must be one. Some of the elements and ideas that were meant to represent and describe parents’ experiences, like ‘being an advocate,’ was becoming more of a criterion of a good parent.<sup>83</sup> In addition, scholars such as Priya Lalvani and Lauren Polvere question that the dominant narrative of parents is embedded in the medical model of disabilities. They write,

The source of the psychological distress experienced by parents is located in their children’s impairments. Conspicuously absent from these studies is reflection on the sociocultural constructions of disability, and the contexts in which the experiences of families are situated. These inquiries also fail to consider how pervasive, deficit-based hegemonic discourses on disability contribute to familial stress and other negative emotions. The perspectives of families of children with disabilities are not represented in this research, as familial experiences are reduced to statistical analyses of negative outcomes.<sup>84</sup>

Lalvani and Polvere specifically point out two themes that are problematic: “notions of profound loss and burden” and “denial” observed in parents’ narratives. This institutional discourse and the medical staffs expect parents to experience profound loss and denial as typical responses, whereas parents’ responses are varied. Professional expectations of loss and denial

---

<sup>81</sup> Goddard, Lehr, and Lapadat, “Parents of Children with Disabilities,” 281.

<sup>82</sup> Goddard, Lehr, and Lapadat, “Parents of Children with Disabilities,” 279.

<sup>83</sup> Goddard, Lehr, and Lapadat, “Parents of Children with Disabilities,” 279.

<sup>84</sup> Lalvani and Polvere, “Historical Perspectives.”

colonize parental experiences, erasing alternative wisdom and experiences that do not emphasize loss or denial and thereby prioritizing the professional's knowledge over parents' wisdom and experience.

None of these publications notice that multiple narratives from different perspectives can operate at the same time within a parent, which causes confusion in understanding the multifaceted narratives of parents. Sometimes parents seem to rely on and benefit from medical perspectives; at other times they reject the medical model in favor of other understandings. This process of accessing multiple narratives was understood as the negotiation of parents. Multiple worldviews are mixed in parents' narratives, and if we can identify those, understanding when and how the worldviews converge and diverge, we can better understand parents' experiences.

The parents' narrative described by Darling in 1979 is still considered to be representative of the narrative of parents, although it received criticism for its assumption that this narrative is embedded in the medical perspective and the way it inadvertently prioritizes the professional's opinion over the opinions of parents. This narrative, regardless of how long ago it was published, identifies common experiences and responses of parents in the process of raising their children. Many of the experiences and responses, such as shock and even trauma, are true of parents when they first face their child's diagnosis. In the narrative, parents desperately seek a cure right after they learn of their child's diagnosis, and only gradually do they to some degree become adjusted to their child's disability and begin to give up the hope of finding a cure. (This pattern was also observed in the experiences of the two mothers I interviewed for this project.) Darling's book is a significant contribution to improve the understanding of parents of children with disabilities, because the narrative she constructs provides common ground for the understanding that exists among parents, scholars who have studied families of children with

disabilities, and those in the positions of providing care. More specifically, parents can better understand why they act or react in certain ways and can make sense of what is happening in their lives. The book's narrative functions as a personal reflection that allows parents to see and understand themselves. (This narrative of the process of coming to accept disability can also be helpful to those who accept their own disability or that of their family members.)

However, this dominant narrative also has limitations in addition to those raised already. The stages or phases, as roughly divided, are inaccurate, although perhaps not so clear-cut. Cases occur, such as that of a mother who went through all these stages from anomic to activist, but some part of her remains open to hope for the cure, at least to a small extent, according to my research participants. In some cases, a mother will continue to have a deep sense of unresolved sadness or disappointment caused by the experience of moving from an anomic to activist stance. Darling's model alone cannot completely account for all of these mothers' experiences. This is the point at which I hope my dissertation, especially chapter 5, will add important information to the discussion.

### **Theologians' Understandings of Mothers of Children with Disability**

I begin this review with theologians' perspectives on family. Don Browning, in *Equality and the Family: A Fundamental, Practical Theology of Children, Mothers, and Fathers in Modern Society*,<sup>85</sup> discusses an ethics of family life in which all family members regard each other in a reflexive and responsible manner within a social system that supports the family.<sup>86</sup>

---

<sup>85</sup> Don Browning, *Equality and the Family: A Fundamental, Practical Theology of Children, Mothers, and Fathers in Modern Societies* (Grand Rapids, MI: William B. Eerdmans, 2007). Browning studied the influence of religion on American family life. See also Adrian Thatcher, *Theology and Families* (Malden, MA: Blackwell, 2007).

<sup>86</sup> Tom Beaudoin, review of *Equality and the Family: A Fundamental, Practical Theology of Children, Mothers, and Fathers in Modern Societies* by Don Browning, *Horizon: The College Theology Society* 37, no. 2 (2010): 364–66.

Bonnie Miller-McLemore in her book, *Also A Mother: Work and Family as Theological Dilemma*,<sup>87</sup> notes the struggles experienced by many working mothers to what degree they have to balance working for family, children, work and for themselves. She criticizes the contradictory images of mothers promoted by popular media and points out their detrimental effects on mothers. Julio Rubio, a Christian ethicist, provides a framework within which to understand the family as a community committed to social justice in *Family Ethics: Practices for Christians*.<sup>88</sup> Recently, *Parenting as Spiritual Practice and Source for Theology: Mothering Matters*, offers an insightful theological understanding of “mothering” as spiritual practice and how intersecting identities such as gender, race, sexuality, and class can influence the practice of mothering. These scholars together reflect their awareness of theologians’ lack of attention to family matters, which are regarded as minor and ordinary. These authors agree that this is problematic because embodied practices occur within the family context, to which almost all people can relate and which has been devalued in the Christian context. In addition, Julia Rubio points out that in theology there has been a tendency to consider family and matters related to family less important or trivial compared to what are regarded as “grand issues” – such as social justice.<sup>89</sup> If family matters are discussed, the mothers’ voices or experiences are rarely reflected, instead being interpreted by male authorities.<sup>90</sup> Also, mothers are most likely to be understood in relation to their children. Mothers rarely see their images or experiences reflected in either Christian tradition or in Christian community. In addition, these studies do not include how disability or mental illness play roles in marriage or family dynamics.

---

<sup>87</sup> Bonnie Miller-McLemore, *Also a Mother: Work and Family as Theological Dilemma* (Nashville, TN: Abingdon Press, 1994).

<sup>88</sup> Julie Hanlon Rubio, *Family Ethics: Practices for Christians* (Washington, DC: Georgetown University Press, 2010).

<sup>89</sup> Rubio, *Family Ethics*, 1–2.

<sup>90</sup> Claire Bischoff, Elizabeth O’Donnell Gandolfo, and Annie Gardison-Moody, eds., *Parenting as Spiritual Practice and Source for Theology: Mothering Matters* (Cham, Switzerland: Palgrave MacMillan, 2017), 1–4.

Parents of children with disabilities began to be noted by only a handful of theologians before 2000, including Kathy Black, Stanley Hauerwas, and Kathleen Greider. Kathy Black notes one of the common, and problematic, responses that parents of children with disabilities receive in their Christian communities: “Parents with disabled children are seen as saints because of the ‘extra burden’ they carry.”<sup>91</sup> The responses and reception given to parents of children with disabilities in the field of theology as observed and noted above is strikingly similar to the way American popular culture describes childhood disability. Like American popular culture, theology also tends to see disability “either as a tragedy arising from a mother’s careless behavior during pregnancy (through drug or alcohol use) or as part of God’s plan to give special kids to special parents.”<sup>92</sup> What is more problematic is that these negative understandings are too often found in public interaction and that devaluation of children with disabilities is often extended to the mother.<sup>93</sup>

Kathleen Greider describes the experiences of families and parents of children with disabilities, who often become the primary caregivers and frequently, become sacrificing of themselves. Greider observes that parents of children with disabilities go through as much emotional pain as the primary sufferers.<sup>94</sup> For example, when a soul-sufferer, a person with mental illness, experiences longer-term anguish, they feel “the unknown, shame and responsibility, social isolation, damaged relationships, and loss and grief.”<sup>95</sup> When this does happen, the loved ones, usually the family— although the degree may vary—also have similar emotions and experiences. “Especially in those cases where the anguish leads to the primary

---

<sup>91</sup> Black, *A Healing Homiletic*, 16.

<sup>92</sup> G. H. Landsman, “Emplotting Children’s Lives: Developmental Delay vs. Disability,” *Social Science & Medicine* 56 (2003): 1947-1960. in Lucie P. Lawrence, “Hardly a Walk in the Park: Examining Disability through a Mother’s Eyes,” *Journal of Loss and Trauma* 13, no. 6 (2008): 530.

<sup>93</sup> Lawrence, “Hardly a Walk in the Park,” 530.

<sup>94</sup> Greider, *Much Madness Is Divinest Sense*, 130.

<sup>95</sup> Greider, *Much Madness Is Divinest Sense*, 129–43.

sufferer's inability to carry out his or her responsibilities, families are weighed down by worry, efforts to help, and extra responsibilities."<sup>96</sup> In addition, helplessness is another major emotion parents feel when they fail to protect their children or feel frustrated when facing the reality of insufficient support from the mental-health system. One parent said after his child took his life: "What was so terrible in our son's life that he felt the need to end his life?"<sup>97</sup> When it comes to suicidality, which includes attempts at suicide and is usually a symptom of mental illness, Greider points out that what the family is left with is usually deprivation of insurance benefits by insurance companies.<sup>98</sup>

Another point raised by Greider—that I think increasingly important, but rarely raised by theologians—is the families' voices that say, at some point, they realize they do not know what and how to feel in relation to their family members who suffer mental illness. This usually happens when caring for a family member whose suffering, at some point, exceeds the family's capacity to provide adequate care. In this case, although feeling deep anger and frustration, the family tries to repress those feelings because those for whom they are taking care are "family." This is partly because the idea of family has been romanticized, to some extent, as a sweet home, and it seems ethically wrong to have feelings against a member of one's family.<sup>99</sup>

While Greider focuses on lived experiences, Hauerwas aims to provide a moral stance to understand children with disabilities, especially in light of a Christian community, because, for Hauerwas, a moral stance toward these children will improve the quality of support they receive.

---

<sup>96</sup> Greider, *Much Madness Is Divinest Sense*, 153–61.

<sup>97</sup> Greider, *Much Madness Is Divinest Sense*, 131.

<sup>98</sup> Greider, *Much Madness Is Divinest Sense*, 148.

<sup>99</sup> For example, in South Korea the term *Gan Buung Sal In* is increasingly being used. It literally refers to a person who kills a family member after devoting herself/himself to caring beyond his/her capacity. Usually, it happens after a long period of repressing emotions while focusing on and performing the role of caregiver.

In this vein, for Hauerwas, taking a right moral stance is part of the care for children with disabilities. He further explains:

For care is not simply ‘doing’ things for these children, even when such ‘doing’ involves our best technologies, but it means knowing how to be with and regard these children with the respect they demand. Thus forms of care with which we approach these children must be guided by our basic beliefs about why we have them at all.<sup>100</sup>

Hauerwas argues that having and raising children with disabilities offers essential wisdom for parenting any children, teaching important skills for parenting in general.<sup>101</sup> He asserts that parenting children with disabilities is not only a gift to parents, but is a gift for a community because of the wisdom the parenting experience offers about God and the essence of Christian community. For example, Hauerwas quotes Berube, who is a father of a son with Down Syndrome. Bereube wrote in his essay, mourning that his only hope is for Jamie (his son) to be his own representative one day. Hauerwas points out this is exactly opposite to the idea of Christian thought which based its ontology in the fact that we, human beings, are creatures. That is, human beings’ ontological status is dependency, not autonomy.

Hauerwas points out that seeing retarded children simply as a blessing fails in sufficiency. He argues that this interpretation is weak because it is based on the extent to which children with disabilities enliven certain families. The right question to ask, he says, is, “What kind of families and communities should we be so we could welcome retarded children [children with disabilities] into our midst regardless of the happy or unhappy consequences they may bring?”<sup>102</sup>

---

<sup>100</sup> Stanley Hauerwas, “Having and Learning to Care for Retarded Children,” in *Critical Reflections on Stanley Hauerwas’ Theology of Disability: Disabling Society, Enabling Theology*, ed. John Swinton (New York: Routledge, 2005), 151.

<sup>101</sup> Hauerwas, “Having and Learning,” 151.

<sup>102</sup> Hauerwas, “Having and Learning,” 150.



Kathy Black and Stanley Hauerwas see these issues from the perspective of a Christian church community. Black briefly offers what is going on – how parents are received – and provide a normative stance that is centered on Christian community. Hauerwas also points this out and offers a normative theological interpretation. These are not simply for parents but also for the church community to provide better care and understanding of parents of children with disabilities and to better understand them from the perspective of community. Greider shows us that family members also become vulnerable emotionally, psychologically, and financially when their family members suffer mental illness. It is important to note that because her book focused on experiences of people with emotional distress, parents are described and researched only to a limited extent.

Now, I turn to the theological notion of hope, the framework I will use to explore the thick description of my research partners, Alice and Karyn, and their worldviews.

### **Genealogy of Hope: The Concept of Hope in Pastoral Theology**

The purpose of this section is to lay the groundwork of Andrew Lester's theological concept of hope for a better understanding of the thick description of my two research partners in chapter 4 and to identify and analyze the movement of hope in different worldviews on disability in chapter 5. For this reason, here, I focus on understanding Lester's framework of hope in pastoral theology, as well as the theological anthropological concepts on which his understanding of hope is based. Lester's theological concept of hope is an effective framework within which to analyze mothers' narratives and, especially, to understand how mothers envision their futures in relation to their children's disabilities. In addition, Lester provides an effective framework that, to some extent, allows us to discern and predict mothers' spiritual well-being

and the psychological effect of different worldviews on disability. While using most of Lester's concepts, such as despair, transfinite hope, and finite hope, broadly, I will add complexity when I apply Lester's framework to analyze the medical worldview in chapter 5 by complicating the understanding of benefits of finite hope. I will argue that, unlike Lester's point, there are some spiritual strengths caused by finite hopes.

The genealogy of hope in the field of pastoral theology is relatively short.<sup>103</sup> Two important books, *Hope in Pastoral Care and Counseling* by Lester, and *Agents of Hope* by Donald Capps, were published in 1995.<sup>104</sup> Unlike Capps's work, in which hopefulness and hopelessness are situated in opposition as Capp distinguishes 'major threats to a hopeful attitude' and 'allies of hope,' Lester uses more nuanced concepts in analyzing the dynamics of hope. Because of his nuanced treatment, I decided to use Lester's framework to facilitate our understanding of the concept of hope and despair and its dynamics for parents of children with disabilities.

## Defining Hope

Although the importance of hope as a resource has been discussed widely—not only in the fields of pastoral care and theology but also in psychology, psychiatry, and philosophy—still it is difficult to conceptualize hope in a few sentences. “Developing an inclusive and adequate

---

<sup>103</sup> For a theological perspective, see Paul Pruyser (psychologist), “Phenomenology and Dynamics of Hoping” ; William F. Lynch, “Images of Hope: Imagination as Healer of the Hopeless,” 5, *Agents of Hope*, Donald Capps. In the field of psychology, see works by Erik Erikson, and in anthropology see works by Gabriel Marcel. These authors conceive of hope as one of the fundamental human drives.

<sup>104</sup> Hope, says Donald Capps, is an attitude or disposition that exists as an integral part of ourselves, whether or not we are entertaining specific hopes at any given time. Its attitudinal quality can be seen in the fact that the vast majority of us maintain a hopeful spirit toward life as we live our life from the implicit conviction or tacit belief that the future is an open one and that it holds possibilities for us. We do not necessarily believe that everything works out for the best, nor are we necessarily optimistic about what the future holds for us. But we are hopeful and act from hope, usually without giving conscious thought to the fact that our disposition is to be hopeful and not despairing. The agent of hope, in Capps's understanding, is the pastor.

definition of hope is difficult,”<sup>105</sup> Lester writes. One reason is hope’s pervasiveness in life in general. It is not easy to sort out the concept of hope expressed in daily life. For this reason, hope is rather explained and defined by description. However, we still need a definition to create a barometer of what we are and are not discussing. When it comes to understanding hope in its most general terms, hope can be described as the action or the thinking process of “anticipating the next moment, the next step – responding to the thought of tomorrow with expectation, even excitement.”<sup>106</sup> In theological terms, Lester argues that hope “describes a person’s trusting anticipation of the future based on an understanding of a God who is trustworthy and who calls us into an open-ended future. This God keeps promises of deliverance, liberation, and salvation.”<sup>107</sup>

### Lester’s Understanding of Hope

In Lester’s understanding, temporality is a foundational human condition on which he has based his discussion. “Temporality” refers to a person’s consciousness of past, present, and future time. Because humans cannot escape the passing of time but are embedded in time, how a person understands what she is experiencing through the passing of time directly and indirectly affects the way she forms her self-identity. In order to understand the present, a person needs to understand both where she is going in terms of what she is hoping for and from where she sees herself coming. That is, self-understanding, which cannot be separated from understanding one’s present, requires integrating all dimensions of one’s past, present, and future. Understanding

---

<sup>105</sup> Andrew D. Lester, *Hope in Pastoral Care and Counseling* (Louisville, KY: Westminster John Knox Press, 1995), 62.

<sup>106</sup> Lester, *Hope in Pastoral Care and Counseling*, 62.

<sup>107</sup> Lester, *Hope in Pastoral Care and Counseling*, 62.

hope also requires a holistic understanding of a person's experience and perception of past, present, and future.

For Lester, pastoral theology is built upon its understanding of human temporality in relation to the "capacity to anticipate the future and to project ourselves into this future."<sup>108</sup>

Then, is there any way for us to distinguish life-giving hope? I would like to focus on four points Lester makes that are important to this research. First is the dynamics of finite hopes and transfinite hope. Second is contributors of despair. Third is hope's rootedness in reality. Fourth is the communal nature of hope.

In discussing how a person can develop hope, Lester says that "the capacity to hope reaches into an open-ended future on the one hand and looks for specific content in concrete objects, events, and relationships on the other."<sup>109</sup> Risking over-simplification of the more concrete idea, Lester suggests there are two different kinds of hope: finite hope and transfinite hope. Finite hope means a desire a person has toward finite objects. Lester draws examples such as "our hope for a pay raise, acceptance into a certain school, a good grade, a positive word from an inquiry."<sup>110</sup> As the term 'transfinite' itself suggests, transfinite hope refers to hopes that transcend the concrete objects of finite hopes. Lester points out that some believe that finite hopes ultimately lead a person toward transfinite hope; however, as we will soon see, this is not necessarily true. Transfinite hope is a hope that is open-ended, not limited to whether or not finite hopes have been achieved.

Transfinite hope, according to Lester, is the necessary condition for finite hope, both to protect a person from being plunged into despair and to contribute to life-giving resources. This

---

<sup>108</sup> Lester, *Hope in Pastoral Care and Counseling*, 23.

<sup>109</sup> Lester, *Hope in Pastoral Care and Counseling*, 63. This argument that Lester makes is based on a phenomenological approach. See his book for more information.

<sup>110</sup> Lester, *Hope in Pastoral Care and Counseling*, 63.

suggests that not all hopes are life-giving. Finite hope without transfinite hope, when broken, can easily lead a person to despair, for the hope rests on something that is changeable and temporal. Instead, transfinite hope is based upon a person's trust in God or the Divine's good will, or in the unfailing Divine, rather than based on hope in finite objects. Thus, even if the finite hope is lost, if a person is still holding on to transfinite hope, the person's hope is safe. Transfinite hope is a hope without concrete ideas or objects, but rather believing in the underlying providence of God. Thus, no matter what appears to happen, a person continues to hold to the faith that the good God will remain constant.

Lester also discusses types of future stories that lead a person to despair. By despair, Lester means "disturbances of the 'hoping process' in which our capacity to hope is lost, blocked, distorted, or in some manner impaired."<sup>111</sup> Lester listed the contributors to despair: loss of future story, reaching the end of a future story, not willing to be a self, failure to claim past and future, being present-bound, enmeshment in a finite future story, facing the void, and having a negative god-image.

Hope is rooted in reality. In other words, hope that is not based on reality is not a hope but a fantasy. The hoping process, imagining possibilities, does not negate the suffering or pain of the present in thinking about the future. Hope that is life-giving offers an open future with possibilities and embraces the present moment. However, there are future stories that are not based on reality, but lead a person to escape from where a person is grounded. These kinds of future stories can seem like stories of hope but they are different in that they are dysfunctional, blinding a person's perception of reality.

---

<sup>111</sup> Lester, *Hope in Pastoral Care and Counseling*, 72.

Lastly, Lester points out the communal aspect of the hoping process. According to Lester, hope is rarely born in isolation. It grows in the context of relationship and, more precisely, in community. This indicates the importance of a communal context and its possible influence on the process of fostering and destroying hope. That is, people learn hope from each other, and this means that learning despair is also possible.

Although Lester rightly pointed out in 1995 that hope may be differently understood and expressed depending on a person's gender,<sup>112</sup> in Lester's own work, hope is understood as a general experience regardless of a person's context and identity. This general understanding of hope is a limit I recognize in Lester's work, but it also offers a possibility for further research. Until the year 2000, the critical contextualization of hope was not done in the field of pastoral theology.

Duane Bidwell's work is a prime model that reflects this changing inclination of the research method toward critical qualitative research in practical theology and pastoral theology. It also contributes significantly to widening the scope of our understanding of hope as a theological concept by conducting research on hope in particular contexts. Bidwell also articulates hope as that which can be experienced and expressed differently depending on the location of a person, including one's social and cultural context, race, gender position, and the interplay of various social, cultural forces. Specifically, Bidwell explores the theological concept of hope "that is grounded in, and accountable to, the experience of particular children living with end-stage renal disease."<sup>113</sup> He points out that previous examinations of hope were for the most

---

<sup>112</sup> Lester, *Hope in Pastoral Care and Counseling*, 8.

<sup>113</sup> Duane Bidwell and Donald L. Batisky, "Identity and Wisdom as Elements of a Spirituality of Hope among Children with End-Stage Renal Disease," *Journal of Childhood and Religion* 2, no. 5 (2011): 3.

part done by focusing on adults' experiences.<sup>114</sup> And for this reason, he argues that the results of previous research may not be a useful spiritual resource to nurture hope for children.

Bidwell proposes that for children who experience chronic illness hope has different qualities than the hope that theologians have understood. Children experience [hope] "as participatory, relational, kinesthetic, perceptual, and – perhaps most significantly – conative. The will – that is, the ability to choose – has a prominent place in their accounts of hope; hope is not a passive experience for them but an active decision that often precedes or informs other dimensions of hope."<sup>115</sup> Practicing an active decision and being mindful of "the fullness of life, relationships, and caring community amidst the finitude of disease"<sup>116</sup> can mean hope for children, and thus these practices can nurture hope.

Bidwell has developed the discussion of hope in pastoral theology by putting the concept of hope in particular contexts, with qualifiers in cases of children and illness. Recently, I undertook research to explore parents' narratives of children with disabilities.<sup>117</sup> My research focused on identifying parents' differing narratives which I categorizes as triumphal and absurd. These label these narratives because of the primary differences represented in "how conflicts develop and are resolved."<sup>118</sup> For example, "the triumphal narrative tends to follow the traditional narrative pattern of conflict, climax, and resolution"<sup>119</sup> and the storyline is most likely to be triumphal. On the other hand, the term "absurd narratives" comes from "the theatre of the absurd, a genre of literature that emerged in the early 20<sup>th</sup> century in Western Europe, because of

---

<sup>114</sup> Bidwell and Batisky, "Identity and Wisdom," 2.

<sup>115</sup> Bidwell and Batisky, "Identity and Wisdom," 7.

<sup>116</sup> Bidwell and Batisky, "Identity and Wisdom," 8.

<sup>117</sup> Jeongyun Hur, "The Stories of Parents of Children with Mental Disabilities: 'Triumphal' vs. 'Absurd' Narratives," *Journal of Pastoral Theology* 27, no. 1 (2017): 47–62.

<sup>118</sup> Hur, "The Stories of Parents," 50.

<sup>119</sup> Hur, "The Stories of Parents," 50.

the similarity of their storylines”<sup>120</sup> where the story ends with ambiguity and story tends to show the sense of absurdity. A prime example of this kind of story is *Waiting for Godot* where two protagonists endlessly waiting for Godot to arrive. In my pastoral theological reflection, I articulate that the two different forms of narrative imply different hopes within the parents of children with disabilities. For example, for those who tell the triumphal narrative, hope was for a healing of disabilities of their children; whereas, for parents who tell the absurd narrative, the outcome of hope was to embrace their children’s lives with the disabilities while striving to improve the quality of their children’s lives. From Lester’s perspective, hope within the triumphal narrative is categorized as finite hope, that is not life-giving in a fundamental sense, whereas hope within the absurd narrative is functional hope in that it doesn’t have a specific goal as a finite hope does, but is opened-ended. It is life-giving hope. My dissertation takes up this theological notion of hope and tries to point out that some finite hopes can also be life-giving in the short-term by demonstrating the function of the medical understanding of disability and the idea of hope imbedded in it through exploring research participants’ narratives and analyzing each understanding of disability. The intersection of disability, theology, and hope provides a theological conversation partner for my first research question: What is the disability theology of parents? With this background, now I turn to method and methodology used to explore this question.

---

<sup>120</sup> Hur, “The Stories of Parents,” 53.



## Chapter 3

### Methodology

While method implies and reveals an intention of the study,<sup>1</sup> it also fundamentally shapes the course and the result of the study.<sup>2</sup> The main goals of this dissertation are to identify points of incongruence between the theologies of mothers of children with disabilities and disability theology and to explore why these incongruences exist and how we can make sense of them. To this end, two main methodological approaches are used. First, practical theological hermeneutics as a framework for dialogue between mothers' experiences and the academically developed knowledge of disability. Second, qualitative research method to understand the experiences of mothers. To better elicit and frame mothers' experiences, I combined discourse analysis, narrative inquiry and narrative therapy. The goal of this section is to articulate these aforementioned two approaches in order. Then, I will describe the process of my research.

#### **Practical Theological Method – Revised Critical Correlation (Pastoral Cycle) – Four Tasks**

Practical theology is committed, as I mentioned in Chapter 1, to explore intrinsic value and provide reinterpretation and reevaluation. R. Ruud Ganzevoort, professor of practical theology at VU University in Amsterdam, in his presidential address at the 2009 International Academy of Practical Theology asserts that the common ground of theological works is found

---

<sup>1</sup> Joretta L. Marshall, "Methods in Pastoral Theology, Care, and Counseling," in *Pastoral Care and Counseling: Redefining the Paradigms*, ed. Nancy J. Ramsay (Nashville, TN: Abingdon Press, 2004), 133–54.

<sup>2</sup> Greider, *Much Madness Is Divinest Sense*, 46.

“in a description of practical theology as the hermeneutics of lived religion,”<sup>3</sup> which I see as a different expression of the reinterpretation of its intrinsic value. Interpretation, from the perspective of practical theology, involves two specific goals. First, to identify and describe transcendence in human practice and, second, to mediate practical tension in the event relevant to religion. Bonnie Miller McLemore captures this task of practical theology:

Ultimately, practical theology is normatively and eschatologically oriented. That is, it not only describes how people live as people of faith in communities and society, but it also considers how they might do so more fully both in and beyond this life and world.<sup>4</sup>

Then, first, how can we identify and describe transcendence in human practice? What is the meaning of transcendence in practical theology? To scholars like Ganzevoort, the experience or practices related to transcendence are at the core of religion. Ganzevoort defines religion as “the transcending patterns of action and meaning embedded in and contributing to the relation with the sacred.... The core of the definition, however, is the relation with the sacred, which is not an endlessly open concept.”<sup>5</sup>

In choosing the terms describing religion, Ganzevoort explains that his choice of words was deliberate in avoiding restriction to the meaning of religions to traditional or institutional religion while honoring the potential to discover new forms of religion and practices. What cannot be compromised is its essence: “The notion of the sacred at least implies that it is a center around which one’s life gravitates and a presence that evokes awe and passion.”<sup>6</sup> This is an important insight in my dissertation as I will propose the potential of mothers’ practical wisdom as a normative value in chapter 6. To me, the sacred phenomenon of mothers is their practical

---

<sup>3</sup> R. Ruud Ganzevoort, “Forks in the Road When Tracing the Sacred: Practical Theology as Hermeneutics of Lived Religion” (presidential address, International Academy of Practical Theology, Chicago, IL, March 8, 2009), 3, <https://www.ia-practicaltheology.org/wp-content/uploads/2011/11/presidentialaddress2009.pdf>.

<sup>4</sup> Bonnie Miller-McLemore, “Practical Theology,” in *Encyclopedia of Religion in America*, ed. Charles H. Lippy and Peter W. Williams, vol. 3 (Washington, DC: CQ Press, 2010), 1739–42.

<sup>5</sup> Ganzevoort, “Forks in the Road,” 3.

<sup>6</sup> Ganzevoort, “Forks in the Road,” 3.

wisdom that enables them to orchestrate different understanding of worldviews all together when needed in order to support various social relationships of mothers and process possible ambivalence associated with contradictory understanding of disability which ultimately sustain mothers' daily life.

Second is to mediate in practice the tension caused by any theological misunderstanding. As I will examine more closely in a later section, Richard Osmer's four tasks stress this aspect by providing systematic categorization that is aimed precisely toward solving the problem. In addition, Elaine Graham proposes that one of the functions of learning 'practical wisdom' is its ability to reveal the limits of status quo theological studies or traditions. Andrew Root, practical theologian at Luther Seminary, made the point that one of the ultimate goals of practical theology is to make a change in action in a way that manifests God's intention and presence through action and practice.<sup>7</sup> In another place, Root quotes Ray Anderson, a professor at Fuller Theological Seminary, in pointing out the intricate connection between practical theology as taking up the role of interpretation and attending to crisis in practice.

Practical theology is essentially a hermeneutical theology. That is to say, theological reflection that begins in the context and crisis of ministry seeks to read the texts of Scripture in light of the texts of lives that manifest the work of Christ through the Holy Spirit as the truth and will of God.<sup>8</sup>

These practical theologians commonly emphasize the positive change that practical theology aims to create because the field of practical theology's "end is participation in the reconciliation and restoration of persons and communities throughout the world."<sup>9</sup>

---

<sup>7</sup> Andrew Root, "Practical Theology: What Is It and How Does It Work?" *Journal of Youth Ministry* 7, no. 2 (Spring 2009): 62.

<sup>8</sup> Root, "Practical Theology," 62.

<sup>9</sup> Root, "Practical Theology," 63.

From the outset, these two goals are contradictory, as the first task generally involves providing or proclaiming affirmation of a certain phenomenon, whereas the second task seeks to provide positive improvement of the quality of lives or the condition of the status quo in regard to theological issues. To fulfill these two goals at the same time requires a sense of balance and sensitive theological consideration. I strike a balance between affirming the intrinsic value and yet I offer a way for positive improvement, which is the task of the theologian.

In order to fulfill this task, I argue that Elaine Graham's critical theology of pastoral practice helps to discern the theological value of a given practice, while Don Browning's revised critical correlation assists in the effort to seek improvement in practices as they are related to theological understanding. Graham's theology will later help me to illuminate what I see as the divine presence, which I will call practical wisdom in mothers' experiences. Browning's revised critical correlation and Osmer's four tasks will help me to come up with my strategy. In my case, this will provide a guide for narrative therapy, allowing me to identify and support mothers' practical wisdom — not because it is a problem, but to encourage potential benefits that highlight and support it.

Let me begin with Elaine Graham's critical theology of pastoral practice. This paradigm of pastoral theology undertakes the task of the theologian, to interpret, discern, and affirm the theological value of certain practices. Graham provides three norms as criterion to discern this. These are narrative, women's experiences, and the pursuit of "liberation or 'promotion of the full humanity of women.'"<sup>10</sup> These elements constitute an important part of my dissertation as a narrative of mothers of children with disabilities in which I fulfill Graham's criterion and what I see as mothers' 'practical wisdom' by which they achieve the theological goal of promoting

---

<sup>10</sup> Elaine L. Graham, *Transforming Practice: Pastoral Theology in an Age of Uncertainty* (Eugene, OR: Wipf and Stock, 2002), 112.

mothers' full humanity by allowing room to exercise their sense of agency. At the same time, Graham asserts that 'practical wisdom' is disclosive in that it reveals the limit of status-quo theology. This is also true for these mothers. Mothers' practical wisdom reveals what current disability theology has valued and not valued — which are the practices of disability theology in mothers' lives and its relation to mothers' agency while supporting their children. I particularly operate from Graham's perspective in exploring mother's practical wisdom, which is the task of chapters 4 and 5.

Within Graham's approach, I use a 'care ethics' approach as a normative ethical theory to understand another quality of mothers— their practical wisdom. The care ethics paradigm provides meaningful and humanistic insights into mothers' practical wisdom. Let me briefly explain the care ethics paradigm. The ethics of care is one of the normative moral theories and is an approach for moral theorization.<sup>11</sup> Care ethics, so-called feminist virtue ethics, has grown out of the cracks of the justice-oriented understanding of morality such as Kantian moral theory, utilitarianism, and virtue ethics<sup>12</sup> to resist its shortcomings and oversights. These traditional ethical normative theories mostly focus on how just the person, or a government, is or whether a person's disposition is justice-oriented. From this perspective, women were considered less just than men because women were believed to have other priorities in mind. The care ethics tradition attempts to see those unnoticed aspects or concerns that are not considered important in other more established ethical theories. The area that feminist care ethicists upholds is the consideration of relational realities within moral issues.<sup>13</sup>

---

<sup>11</sup> Virginia Held, *The Ethics of Care: Personal, Political, and Global* (Oxford: Oxford University Press, 2007), 3.

<sup>12</sup> Held, *The Ethics of Care*, 3–4,

<sup>13</sup> Held, *The Ethics of Care*, 4.

While Graham's critical theology of pastoral practice and the care ethics approach offer the necessary framework within which to identify the value of mothers' practices, Browning's revised critical correlation provides the perspective to explore the gap between mothers' experiences and what is studied in academia. This is congruent with Graham's understanding of one of the functions of practical wisdom — that it unpacks the limits of current theology. Browning's revised method is one of the most-often-used methods in practical theology; it has as its main goal to construct a dialogue between theory and practice. It is also referred to as the pastoral cycle. It was developed by Paul Tillich and revised by later theologians David Tracy and Don Browning. While the pastoral cycle has gone through revision, the essence is that it "goes from practice to theory and back to practice."<sup>14</sup> For Browning, particularly, it is a dialogue which begins from "present theory-laden practice" and moves to "a retrieval of normative theory-laden practice."<sup>15</sup> Through interaction between these two sources, the dialogue aims for "the creation of more critically held theory-laden practices."<sup>16</sup> The revised correlational method is also usually used when there is a crisis in need of a support. Facing that crisis as part of seeking support, theologians "reexamine the sacred texts and events that constitute the source of the norms and ideals that guide its practices."<sup>17</sup> Then, "the theologian brings this question to these normative texts" to construct a dialogue between questions the theologian brought from previous practice.<sup>18</sup> Browning's revised method provides a perspective to understand human experience in light of theoretical knowledge and vice versa. It doesn't stop simply at the effort to "understand" both sides, but attempts to influence positively both knowledge and practice.

---

<sup>14</sup> Don S. Browning, *Fundamental Practical Theology: Descriptive and Strategic Proposal* (Minneapolis: Fortress Press, 1991), 7.

<sup>15</sup> Browning, *Fundamental Practical Theology*, 7.

<sup>16</sup> Browning, *Fundamental Practical Theology*, 7.

<sup>17</sup> Browning, *Fundamental Practical Theology*, 6.

<sup>18</sup> Browning, *Fundamental Practical Theology*, 6.

According to Browning, this critical dialogue makes it possible to make sense of communities and disclose whether and how they employ practical wisdom.<sup>19</sup> Once theologians have identified the level of practical wisdom that is operating in certain communities, theologians can support the community as it begins to enact a new set of practices that are decided on as a result of constructive dialogue. These new practices continue until this community meets a new crisis.<sup>20</sup> Browning adds, “our overheated and repeatedly changing technological societies are requiring us to turn these corners of cultural deconstruction and reconstruction more often.”<sup>21</sup>

This captures the reality that mothers of children with disabilities experience. For example, for Alice and Karyn—mothers whom we will see in the next chapter, and who are in the process of facing and helping to cure their children’s disability—medical technology holds an important place in their lives. To some degree, medical technology had indeed significantly helped Karyn’s daughter to gain ability and to discard disability. However, in Alice’s case, she was told by medical professionals that the development of medical technology would cure her son’s disability within 10 years—but that didn’t happen, which resulted in her frustration. Children’s disability inevitably brings to mothers’ attention the issue of ever-developing yet limited technology and creates the demand for some kind of relationship with the medical perspective. Furthermore, their children use medical technology in their daily lives. Alice’s son Julius, for example, relies on technology for mobility; Karyn’s daughter Corbyn receives therapy that uses the most up-to-date technology. As we will see in chapter 5 (thick description) and chapter 6 (analysis), mothers are well-aware of and very interested in the development of the

---

<sup>19</sup> Browning, *Fundamental Practical Theology*, 94–97.

<sup>20</sup> Browning, *Fundamental Practical Theology*, 6.

<sup>21</sup> Browning, *Fundamental Practical Theology*, 7.

fields of medicine and science. Given this reality, the role of theologians is to explore, evaluate and provide suggestions for mothers that can sustain and promote mothers' functional understanding and relationship with medical and scientific technology, which I will address in chapter 5.

Going back to the dialogue between 'human experience' and 'text,' my organic experience that has led me to embark on this research aligns with Don Browning's revised critical correlation method. I must explain how this research grew following the order of the revised critical correlation method, although I didn't intend such. In the first year of my Ph.D. program, I enrolled in an ethnographic research method class at Claremont Graduate University and happened to choose the topic of exploring the experiences of parents of children with disabilities. The qualitative research was fascinating. In the research for the class, which now I can see as the pilot research for this dissertation, I focused on parents' experiences. I didn't know much about disability theology at that point. I happened to have many chances to present my research, and in the process of preparing for presentation, I had to look into what is called disability theology, with the specific agenda raised by the experiences especially of mothers: Can disability theology offer resources to affirm the experiences of mothers of children with disabilities? During this process, I began to see the apparent differences between how parents understand disability and how scholars talk about disability. They share significant similarities, in a loose sense, yet disability theology, I found, was not sufficient to reflect the richness and complexity of parents' lived theology. I wondered why this happened and began to question the elements missed by scholars in disability theology. This process that I experienced, unplanned and unconsciously, is "revised critical correlation" in that I see a "parent's experience and lived theology" as referring to members of a community and "disability theology" as referring to texts



of Christian theology — and I see both as equal partners in a dialogue. Through the dialogue, my dissertation develop “the creation of more critically held theory-laden practices.”<sup>22</sup>

#### Four Tasks

Four tasks of practical theology, identified by Richard Osmer, effectively assist the process of revised critical correlation by providing categories that systematically classify theological knowledge in four ways. These are the “descriptive-empirical,” the “interpretive,” the “normative,” and the “pragmatic”<sup>23</sup> which categories I broadly follow in my dissertation.

The first task, the descriptive-empirical, provides details of what is going on within a specific situation, which is going to be chapter 4 of this dissertation. The goal of that chapter is to present and discern patterns and dynamics of particular episodes, situations, or contexts via thick description<sup>24</sup>; specifically, in my dissertation, the lived theology of mothers of children with disabilities. In doing so, I also provide some of my interpretations of what mothers are experiencing in addition to why and how they come to think in certain ways. This chapter sets the tone for Chapter 5, titled Analysis, in which I will try to answer the main questions of my dissertation.

The second interpretive task, which will be chapter 5 of my dissertation, also provides data on what is going on; however, this task provides more in-depth systematic analysis to answer the question of *why* this is happening. Furthermore, in the process of exploring why, the practical theologian can be helped by using an interdisciplinary conversation partner such as arts and sciences to better understand and explain why these patterns and dynamics are occurring.

---

<sup>22</sup> Browning, *Fundamental Practical Theology*, 7.

<sup>23</sup> Richard Osmer, *Practical Theology: An Introduction* (Grand Rapids, MI: William B. Eerdmans, 2008), 4.

<sup>24</sup> Osmer, *Practical Theology*, 4.

For example, I employ theories of disability that are highly interdisciplinary, including a social analysis of disability as well as medical and economic perspectives.

Third, the normative task offers perspectives on the specific situation in its theological context by paying attention to episodes and situations and begins to construct ways, including practices, to respond. Osmer explains that this task generally involves constructing ethical norms to guide our responses, learning from “good practice.” In my dissertation, this will be Chapter 6 where I articulate on practical wisdom of its communal and psychological benefits.

Lastly, in the pragmatic task, the practical theologian develops practices in response to concrete situations. Here, theologians determine strategies of action that will influence situations in ways that are desirable and will allow them to enter into a reflective conversation with the “talk back” emerging when they are enacted.”<sup>25</sup> In my dissertation, as strategies of action, I offer a narrative therapy guideline for mothers of children with disabilities in Chapter 6. This constructive proposal is inspired by what I saw as the practical wisdom of mothers.

To sum up, I argue that to explore mother’s lived disability theology, practical theological hermeneutics offers the best support to engage dialogue between mothers’ lived experiences and disability theology by the frame of revised critical correlation. In doing so, I focus on the practical wisdom of mothers assisted by theories from Graham’s pastoral theology and the care ethics tradition. Now the question becomes, How can I elicit and explore mothers’ experiences as legitimate data? To answer this, I now turn to narrative inquiry, discourse analysis and narrative therapy as qualitative methodologies.

---

<sup>25</sup> Osmer, *Practical Theology*, 4.

## **Qualitative Research – Discourse Analysis, Narrative Research, and Narrative Therapy**

Qualitative research is conducted when “a problem or issue needs to be explored,”<sup>26</sup> especially when there is “a need to study a group or population, identify variables that cannot be easily measured, or hear silenced voices.”<sup>27</sup> To some degree, this starting point is similar to that used by theologians to revise critical correlation when scholars found the need to explore given agendas closely. Qualitative research is interested in addressing the meaning that individuals or groups ascribe to a social or human problem. These attributes of qualitative research are suitable for use in answering this dissertation’s question. I am focusing on mothers’ lived theologies, especially on the meaning they ascribe to the notion of different understandings of disability, because it will likely be difficult to examine that knowledge with anything other than a method of qualitative research, because mothers’ lived theologies and experiences are constituted through languages and vocabularies that ascribe meaning. Exploring the meaning people ascribe often involves tackling complexities that cannot easily be captured by quantitative research. Creswell continues to explain that qualitative research is appropriate when “we need a complex, detailed understanding of the issue.”<sup>28</sup> This is the case for mothers of children with disabilities. As explored in chapter 2, current disability theology and psychosocial literature is insufficient in addressing the nuance and complexities of mothers’ disability theology; for instance, the possibility of the coexistence of multiple understandings of disability and why current normative theological understandings of disability do not make sense to mothers, which I aim to uphold in my dissertation. Mothers’ ideas of disability are neither linear nor simple; various seemingly irreconcilable ideas coexist, which need to be analyzed, accounted for, and reflected in

---

<sup>26</sup> John W. Creswell and Cheryl N. Poth, *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*, 4<sup>th</sup> ed. (Thousand Oaks, CA: SAGE, 2017), 45.

<sup>27</sup> Creswell and Poth, *Qualitative Inquiry*, 45.

<sup>28</sup> Creswell and Poth, *Qualitative Inquiry*, 45.

theological sources. The complex inner world of parents points to a need for detailed explorations of why and how their lived theology of disability has become constructed precisely as it is.

For this reason, I employ the qualitative research approach to my inquiry; carry out the collection of data in a natural setting that is sensitive to the people and places under study; and conduct data analysis that is both inductive and deductive and establishes patterns or themes.<sup>29</sup> I argue that among many qualitative research methods, discourse analysis and the narrative research method provide the most appropriate tools to analyze, deconstruct and reconstruct mothers' lived theologies because of the given methods' commensurability with the form of "narrative" and their sensitivities to the constructiveness of narrative. Qualitative approach also provides a methodological tool, a framework, to understand mothers' narratives against or in relation to the grand narratives of disability theology and narrative provided by psychosocial literature. For this reason, this dissertation employs discourse analysis and narrative inquiry as elements of a qualitative research method intended to elicit the 'lived experiences' of mothers for its strength in exploring 'meaning' and 'complexities' that can hardly be reduced to research methods other than qualitative. I also use narrative therapy when developing questions for research participants and interpreting and analyzing research partners' stories because of the philosophical and therapeutic strength of narrative therapy in identifying and amplifying subjectivity of a person. Narrative therapy helps frame the questions to focus on a person's subjectivity; through the question I intend to affirm mothers' subjectivity and at the same time help to gauge to what degree they conceive of their subjectivity.

---

<sup>29</sup> Creswell and Poth, *Qualitative Inquiry*, 44.

Before delving into each method, it is crucial to understand the common interpretive paradigm that undergirds the discourse analysis, narrative inquiry, and narrative therapy in this dissertation. John W. Creswell and Cheryl N. Poth point out that “whether we are aware of it or not, we always bring certain beliefs and philosophical assumptions to our research.”<sup>30</sup> I will employ a social constructivism method to conduct qualitative analyses. The essence, or in other words, the ontological belief, of social constructivism is that one’s sense of reality is socially constructed “by the observer and is not an external entity entirely separate from the observer.”<sup>31</sup> It is within this perspective that the notion of ‘multiple realities’ is possible, as people can construct their own realities. One’s sense of reality is “constructed through our lived experiences and interactions with others.”<sup>32</sup> In order to explore these realities, it is necessary to examine participants’ experiences. Social constructivist researchers ask questions about how participants experience the world and how participations experience the nature/character of society. The ultimate goal of these questions is “to understand the world in which [participants] live and work”<sup>33</sup> In doing so, researchers seek to understand and interpret the meanings participants ascribe to the world in which they live. Creswell describes many different dimensions of meanings participants ascribe to the world that are pertinent to my dissertation. He explains how meanings can be directed to certain objects or things and are usually a result of social or historical negotiations that are created and developed through individuals’ interactions with others as well as the cultural or historical norms prevalent in individuals’ lives.<sup>34</sup> These varying

---

<sup>30</sup> Creswell and Poth, *Qualitative Inquiry*, 15.

<sup>31</sup> Gallant (1993), 19, quoted in Goddard, Lehr, and Lapadat, “Parents of Children with Disabilities,” 273–89.

<sup>32</sup> Creswell and Poth, *Qualitative Inquiry*, 35.

<sup>33</sup> Creswell and Poth, *Qualitative Inquiry*, 35.

<sup>34</sup> Creswell and Poth, *Qualitative Inquiry*, 24.

dimensions of ascribed meaning are the reason why recognizing the social and familial background of participants is important to understand participants' realities.

Olsen's idea that constructivism impacts how a disability is described is pertinent to the way my dissertation employs the meaning of disability. Olsen emphasizes that within the understanding of disabilities, different conditions "are perceived and accommodated within particular social and historical contexts."<sup>35</sup> The presence of different conditions does not mean Olsen denies the existence of "measurable conditions of physical or mental impairment."<sup>36</sup> Rather, he argues that "individual stories about disability are shaped by larger cultural narratives about the value of being functionally different."<sup>37</sup>

This philosophy of how people construct their experiences and understand their realities is important to my dissertation as I move forward to Chapter 6: Constructive Proposal. The guidance of narrative therapy that I offer for these mothers takes advantage of the perspective that reality is not absolute but constructed. If reality is constructed, then it is possible to deconstruct and reconstruct it; ultimately, reality is open to be changed. I will create this generation of new realities or experiences through my constructive proposal. The next section will explore each of these more closely.

## Discourse Analysis

Discourse analysis is a useful tool for my work in that it, first, allows a framework of 'discourse' within which to understand mother's lived theologies and how effective comparison can be made between 'discourse of mothers lived experience' and 'scholarly discourse about

---

<sup>35</sup> Creswell and Poth, *Qualitative Inquiry*, 24.

<sup>36</sup> Creswell and Poth, *Qualitative Inquiry*, 24.

<sup>37</sup> Creswell and Poth, *Qualitative Inquiry*, 24.

parents/mothers of children with disabilities.’ And, second, its assumption is that some kinds of discourse are embedded in social context. The discourse is socially constructed. In this section, I focus on how ‘mother’s narratives’ can be understood as a discourse to explore the deeper dynamics of meanings that mothers ascribe to their daily practice and action which constitute mother’s lived theologies.

Discourse analysis is “the close study of language and language used as evidence of aspects of society and social life.”<sup>38</sup> It is specifically interested in how people’s social lives are “shaped and constrained by... social contexts.”<sup>39</sup> To understand ‘people’s social lives,’ discourse analysis uses ‘discourse’ as a major text and form because the method of discourse analysis is undergirded by the assumption that certain forms of discourse can imply and suggest information relevant to its social context or the social phenomena in which the discourse took place. What is important for discourse analysts is that it does not attempt to excavate or check the truth of any version or claim but tries to understand how and what is constructed.

Then, what can be considered as a discourse? One of the major goals of discourse analysis is “to explore these everyday situations and practices as part of larger processes and social phenomena.”<sup>40</sup> In discourse analysis, both language and non-linguistic elements such as “‘ways of acting,’ ‘spaces and materials,’ ‘values and beliefs,’ ‘gestures,’ and ‘body positions’”<sup>41</sup> can be understood as ‘discourses.’ Recently, the scope of discourse is expanding to include photographs and film as forms of representation on their own or as resources used alongside other practices.<sup>42</sup> These resources become evidence that is part of the picture for certain social

---

<sup>38</sup> Creswell and Poth, *Qualitative Inquiry*, 7–8.

<sup>39</sup> Creswell and Poth, *Qualitative Inquiry*, 3.

<sup>40</sup> Creswell and Poth, *Qualitative Inquiry*, 54.

<sup>41</sup> Creswell and Poth, *Qualitative Inquiry*, 17.

<sup>42</sup> Creswell and Poth, *Qualitative Inquiry*, 3.

phenomena.<sup>43</sup> As such, discourse analysis “emphasizes practice but also contains the notion of a discourse as a resource which makes available ‘ways of talking, acting’ and so on, linked to the performance of an identity associated with a group.”<sup>44</sup> In the case of my dissertation, I consider mothers’ ‘narratives’ as a form of discourse. In closely examining mothers’ narratives, I pay attention to mothers’ meaningful social practices or thoughts revealed through “‘ways of acting’, ‘spaces and materials’, ‘values and beliefs’, ‘gestures’, and ‘body positions’”<sup>45</sup> in their everyday lives.

Through exploring the aforementioned materials as discourse, discourse analysis attempts to generate cultural understanding of specific social phenomena. Stephanie Taylor articulated specific themes of discourse that an analyst would be particularly interested in, which is a framework that has also helped me to specify what I will shed light on, relative to the mothers’ narratives.

The first is the exploration of *social meanings* as systems or aggregates, accrued over time. The second is the study of *meaningful practices*, such as inviting, declaring, threatening, and writing, signing, witnessing, consulting a lawyer, entering a contract and many other practices. The third concerns *the use of language for the communication of meaning*. All three sections adopt a broad approach and at some points juxtapose theorists who are usually associated with separate traditions of academic work.<sup>46</sup>

These provide useful frameworks for my dissertation especially when I analyze and offer interpretative framework in Chapter 5. Social meanings, meaningful practice, and the use of language for the communication of meaning are regarded as significant tasks to explore in order

---

<sup>43</sup> Creswell and Poth, *Qualitative Inquiry*, 3.

<sup>44</sup> Creswell and Poth, *Qualitative Inquiry*, 17.

<sup>45</sup> Creswell and Poth, *Qualitative Inquiry*, 17.

<sup>46</sup> Creswell and Poth, *Qualitative Inquiry*, 8.



to understand social phenomenon. In my case, as we will see detailed in chapter 5, “Analysis,” I consider mothers’ having multiple models of disability theology as a meaningful practice that entails special social meanings for mothers. We will also see that the meanings mothers ascribe to different models of disabilities are communicated through the activities of mothers. I will use the discourse of mothers to elicit information about society or social phenomena.

We have seen that the major question of this dissertation begins with how the mothers’ theologies and the disability theology that is published in academia are incongruent. In order to identify these incongruences and explore the gap between them, I will use revised critical correlation. My research question and the method of revised critical correlation inevitably entail an activity of comparison. Discourse analysis, as a qualitative research method, can assist revised critical correlation because of its two methodological strengths: first, it provides the framework of “discourse” to understand human experience. In my context this refers to “mothers’ lived experiences and theology” and “disability theology” developed in academia. Second, its goal to generate cultural knowledge about a specific social phenomenon; in this case, the context of mothers caring for their children in the contemporary United States. So far, I set the larger frame of my qualitative research by conceptualizing ‘mothers’ experiences and their narratives’ as a discourse that will engage in a dialogue with another discourse of ‘literature that discuss(es) mothers’ of children with disability in disability theology.’ Now, I turn to narrative inquiry to get a closer look at the discourse of ‘mothers’ experience’ through exploring their narrative.

### Narrative Inquiry

Discourse analysis provides an effective framework within which to draw a boundary of experiences that make it effective to compare two different discourses from different contexts,

“Mother’s Lived Theology” and “Disability Theology.” Narrative inquiry helps to elicit data from mothers’ lived theologies by providing an operative approach to understanding mothers’ experiences in narrative form and transforming them into theological knowledge.

Narrative research as a qualitative method specializes in examining narratives. Narrative research understands narrative “as a spoken or written text giving an account of an event/action or series of events/actions, chronologically connected”<sup>47</sup> and “begins with the experiences as expressed in lived and old stories of individuals.”<sup>48</sup> Stories become “field texts”<sup>49</sup> that show individual experiences and shed light on the identities of individuals and how they see themselves.<sup>50</sup>

The findings of narrative inquiry usually deliver “the specific form of the narrative of an individual, and it is told chronologically, highlighting some of the tensions in the story.”<sup>51</sup> Narrative research focuses on narratives as ‘phenomena’ as well as why and how a narrative (phenomenon) is constructed. Researchers pay attention to “details about the specific organization in which the individual’s story takes place”<sup>52</sup> because these details become important contextual information.<sup>53</sup> Through this process, narrative research enables the researcher to analyze deeply and critically the factors that construct the narrative of mothers’ lived theologies. Narrative inquiry’s focus on the constructiveness of the story aligns with the perspective of discourse analysis that looks at discourse as embedded within a certain social context. In examining the constructiveness, narrative research also focuses on the context in

---

<sup>47</sup> Creswell and Poth, *Qualitative Inquiry*, 45.

<sup>48</sup> Creswell and Poth, *Qualitative Inquiry*, 67.

<sup>49</sup> Creswell and Poth, *Qualitative Inquiry*, 71. The authors’ use of the term “field texts” is from Jean Clandinin and F. Michael Connelly, *Narrative Inquiry: Experience and Story in Qualitative Research* (Jossey-Bass, 2004).

<sup>50</sup> Creswell and Poth, *Qualitative Inquiry*, 71.

<sup>51</sup> Creswell and Poth, *Qualitative Inquiry*, 70–71.

<sup>52</sup> Creswell and Poth, *Qualitative Inquiry*, 70–73.

<sup>53</sup> Creswell and Poth, *Qualitative Inquiry*, 65.

which the narrative evolves. For example, “Temporality becomes important for the researcher’s telling of the story within a place. Such contextual details may include descriptions of the physical, emotional, and social situations.”<sup>54</sup> It is because “narrative stories occur within specific places or situations”<sup>55</sup> that “being context-sensitive is considered essential to narrative inquiry.”<sup>56</sup>

Priya Lalvani and Lauren Polvere propose narrative inquiry as an effective methodological tool to support delivering experiences and voices of families of children with disabilities because of its strength to understand the embeddedness of disability in each sociocultural context.<sup>57</sup> Building on this work, through narrative research, I explore the constructiveness of mothers’ lived theologies and how mothers’ narratives – especially reflecting their lived theologies – challenge the theological and psychosocial grand narratives of disability, children, and care. As I will focus on looking at mothers’ experiences as authoritative voices that can inform Christian theology, this perspective is also congruent with practical theological hermeneutics where it contains the perspective that sees mothers’ experiences as practical wisdom. Within this large arch of practical theological hermeneutics, I use narrative research as a method to elicit the experiences of mothers through qualitative research. I also attempt to offer narratives of those mothers of children with disabilities who are not sufficiently addressed in theological studies, especially on maternal (or parental) understandings of disability and care. In addition to the stories told, narrative research is interested in the context in which the narrative is embedded because narrative research also aims to explore “the social, cultural, familial,

---

<sup>54</sup> Creswell and Poth, *Qualitative Inquiry*, 69.

<sup>55</sup> Creswell and Poth, *Qualitative Inquiry*, 69.

<sup>56</sup> Czarniawska (2004), quoted in Creswell and Poth, *Qualitative Inquiry*, 72.

<sup>57</sup> Lalvani and Polvere, “Historical Perspectives.”

linguistic, and institutional narratives within which individuals' experiences were, and are, constituted, shaped, expressed and enacted.”<sup>58</sup>

## Narrative Therapy

Narrative therapy, a practice of psychotherapy, is a school of thought that guides my construction of interview questions, the interview process, and provides an interpretive lens for viewing the data, such as how I analyze data, and understand mothers' subjectivity. Narrative therapy also shapes my stance as a researcher by influencing how I see the subjectivity of mothers rather than as simply those who support and stand behind their children. Narrative therapy was first developed by Michael White and David Epston and further developed by Stephen Madigan during the 1970s and the 1980s. Let me introduce its philosophical backbone before I go on to explain the practice of narrative therapy.

The primary theoretical foundation of narrative therapy is postmodernism (or deconstructionism), especially in regard to Michael Foucault's understanding of social constructivism, truth, and the inseparability of power and knowledge within it. Foucault maintained a social constructionist view of reality. For Foucault, reality is neither fixed nor essentialized. For this reason, there is no truth but only “interpretation of truth.”<sup>#</sup> What is regarded as truth is instead the “constructed ideas that are afforded a ‘truth status’”<sup>59</sup> but do not have an objective reality. That is, Foucault strongly denied the essentialization of truth and proposed the constructiveness of what people “consider” truth. These truths become what are

---

<sup>58</sup> Lalvani and Polvere, “Historical Perspectives,” 68.

<sup>59</sup> Stephen Madigan, *Narrative Therapy*, Theories of Psychotherapy (Washington, DC: American Psychological Association (2010), 34.

regarded as “the standards of normalization and have influence on how people shape their lives and view themselves.”<sup>60</sup>

Construction of discourse on what determines normal and abnormal becomes ‘knowledge.’ Uneven social and political power has the capacity to decide what is and who is normal and abnormal, and what becomes ‘knowledge’ is most likely associated with more power. In the process of the construction of knowledge, he saw that “human beings are objectified as subjects.”<sup>61</sup> For this reason, Foucault attempts deconstruction of human practices and society of structure as those are not naturally constructed, but are rather instituted with specific intention and beliefs through science, psychology, religion and moral law.<sup>62</sup> One of Foucault’s major goals was to deconstruct these “culturally constructed discourses and representations of what we as a society viewed as normal and abnormal among our community of individuals/citizens.”<sup>63</sup>

The constructed ideas that gained the status of truth through power are referred to as belonging to “global knowledge.” What is considered to be global knowledge is also considered to be the norm of society. There is a counter-concept to global knowledge: “local knowledges” or “disqualified knowledges.”<sup>64</sup> Local knowledges, as Madigan understands Foucault, are “alternative knowledges that raise questions about prevailing ideas and practices that are often silenced through their disqualification.”<sup>65</sup> Foucault called these disqualified knowledges, local knowledges. These knowledges are disqualified most likely by being viewed as “different”<sup>66</sup> by

---

<sup>60</sup> Madigan, *Narrative Therapy*, 34.

<sup>61</sup> Madigan, *Narrative Therapy*, 34.

<sup>62</sup> Madigan, *Narrative Therapy*, 25.

<sup>63</sup> Madigan, *Narrative Therapy*, 28.

<sup>64</sup> Madigan, *Narrative Therapy*, 33.

<sup>65</sup> Madigan, *Narrative Therapy*, 33.

<sup>66</sup> Madigan, *Narrative Therapy*, 43.

major groups of people. However, it is these local knowledges that “survive and rise above,”<sup>67</sup> said Madigan.

This is where narrative therapy can intervene to disrupt the internalized global knowledge or what society has lifted up as truth and norm in Foucault’s understanding, or in Elaine Graham’s phrase “grand narrative,” constructed against a person’s subjectivity and unique identity. Because “a knowledge practice viewed as truth within a cultural discourse sets standards,”<sup>68</sup> it affects individuals in shaping their lives and stories.<sup>69</sup> “Once an individual becomes integrated into society’s discourse, certain cultural truths are assumed and privileged, thereby restraining the construction and acceptance of alternatives.”<sup>70</sup>

In order to disrupt global knowledge, the dominant discourse embedded in individual’s lives and stories, a narrative therapist attempts to identify global knowledge first to deconstruct and make room for reconstruction of a new narrative, which is “often subjugated as “less dominant, less scientific, or perhaps less accepted truths,”<sup>71</sup> truthful to a person’s genuine experiences that fully affirm one’s subjectivity. Stories, narratives, become means to this goal. Madigan and White are hopeful and committed to the idea that “individuals are actually uniquely placed to challenge, resist, and subvert the operations of modern power,”<sup>72</sup> “despite the pervasiveness and effectiveness of power.”<sup>73</sup>

In the previous section, one of the reasons I mentioned identifies why I chose narrative research as my qualitative research method. It was because of narrative research’s assumption regarding the constructiveness of narrative. I also mention that the three qualitative research

---

<sup>67</sup> Madigan, *Narrative Therapy*, 34.

<sup>68</sup> Madigan, *Narrative Therapy*, 34.

<sup>69</sup> Madigan, *Narrative Therapy*, 35.

<sup>70</sup> Madigan, *Narrative Therapy*, 35.

<sup>71</sup> Madigan, *Narrative Therapy*, 35.

<sup>72</sup> Madigan, *Narrative Therapy*, 35.

<sup>73</sup> Madigan, *Narrative Therapy*, 35.

methods I am employing, in fact, all shared the element of social constructiveness. Just like narrative research, narrative therapy shares this perspective, and further provides tools to understand how a person has come to the process of constructing the kinds of narratives and to understand the relationship between them and the social, cultural backdrop.

Because of the practice of deconstruction and reconstruction of personal stories that is generated by the post-modern understanding of how the world is constructed, a therapist can assist by empowering a person to create and discover her own story. The practice of deconstructing stories and identities given or imposed by others and creating one for herself is not merely a practice of story-creating. Through this practice, a person gains a whole new perspective that allows her to see the world around her and herself. She can at least begin to conceive of herself as a person who is not subjugated by anyone or any system but fully herself. Because of these powerful therapeutic functions, narrative therapy has been adopted by such eminent pastoral theologians as Andrew Lester, Duane Bidwell, Christie Neuger, Karen Scheib, and Suzanne Coyle.

Ultimately, narrative therapy is not only an effective way of counseling, but also can be integral to understanding the experience of parents of children with disabilities and to conceptualize the complex reality of that experience because of narrative therapy's perspective on seeing mothers as a subject by differentiating their problem and their selves. My dissertation employs the therapeutic practice of narrative therapy with specific intention and commitment. Especially, I was mindful of the therapeutic practice when I designed questions for mothers and when I analyzed their narratives within the framework of models. It is because I consistently attempt to see the relationship of mothers within each model of disability.

## Research Design

Originally this research was planned to be ethnographic research, because I wanted to explore the parental relationship between mothers and their children and include some programs designed by non-profit organizations in the United States in addition to mothers' stories. However, right before I had planned to make a trip to the United States, the Covid-19 pandemic broke out, which prevented me from making the trip and led me to take another route: narrative inquiry.

### Recruitment

The recruitment process, to some extent, revealed many aspects of my research process and the reality of parents of children with disabilities. As I mentioned in the Introduction, my first qualitative research for the class "Ethnographic Research Method" focused on parents' lived experiences and has been published in the *Journal of Pastoral Theology*. Then a year later, in another class, "Qualitative Research Method for Practical Theology," I did a narrative inquiry on caregivers of children with disabilities. My original idea for this class project was to deepen my research that I had already done on parents' lived theologies. I searched for parents who were willing to be interviewed through AbilityFirst, an organization in Claremont. For multiple reasons, it wasn't easy to find parents of children with disabilities who were willing to be interviewed. Some said it would be too emotionally draining, and others said that they literally did not have time for it because they must care for their children, which was a major cause for me to focus on caregivers instead of parents.

This meant that before I even began the dissertation research, I knew that it would not be easy to recruit parents for the interview. I, as a researcher, wanted to recruit participants from



diverse class backgrounds; however, the recruitment process didn't work in that way. I contacted various nonprofit organizations; however, the answer was exactly the same I had been given three years before. In addition, as we will hear from Alice, the Covid-19 pandemic doesn't overlook people with disabilities; the pandemic took away caregiving services from families of children with disabilities, placing care in the hands of parents. This made parents busier so they actually did not have time for interviews. This was another hint for me about the need of support for parents of children with disabilities.

Two participants were willing to be interviewed for my dissertation project: Alice and Karyn – both of whom agreed to use their actual names in my dissertation. Alice was a participant in one of my earlier projects. One of my classmates at that time, who was in the field of fine arts at CGU, had referred her to me. Because I knew she would be willing to participate in another project, I contacted her, and she agreed.

Karyn, another participant, was referred to me by a person in an online community of disability studies that I have participated in for years. As an international student, what I sensed as distinctive – while conducting several research projects on the issue of disability and through my research process – is that disability-related communities in the United States are well established compared to South Korea, and people actively participate in them. I learned about one local community when I was taking a course in disability studies at UCLA. I let go of my desire to find participants who were working-class women. Through the disability community I was able to find Karyn and Alice. I arranged to meet each woman twice for around a 70-minute Zoom interview each time. Both women were mothers and identified as coming from middle-class families according to the survey that I asked them to fill out prior to interview, which changed the focus of my research. While writing my proposal, I had intended to focus on both

parents, rather than only mothers. Perhaps because I am a woman, I had noticed already during my pilot research that mothers were more open to participating in the interview. I also wanted to recruit parents from diverse class backgrounds – including, income and education – to examine how individuals in difference classes construct their lived theology. However, both participants of my research turned out to be from the middle class, both had earned master’s degrees, and both were working mothers. The master’s degrees signaled to me that they were not only able to afford higher education but were able to pay the opportunity cost for those times. Perhaps those with more socio-economic resources have time and emotional room for an interview. For a woman to have a voice, she needs “a room of her own (with key and lock) and enough money to support herself”<sup>74</sup> to quote Virginia Woolf. That is to say, both mothers do own social capital. These socio-economic backgrounds of these mothers help me, as a researcher, to narrow down my analysis; yet they also impose a limitation. I am aware that different socio-economic contexts will lead mothers to have different lived experiences and perhaps, different lived theologies. Exploring the class differences in understanding and experiencing disability is a topic for future research that must be done.

There were some emotions that I felt that I need to address. Before conducting an interview, fear was one of the major emotions, and ‘indescribable uncomfortableness’ during analyzing and interpreting the data of mothers. Every time I felt the similar emotion, I practice “phenomenological epoche” that is also known as “bracketing” in phenomenological research. It is “a process involved in blocking biases and assumptions in order to explain a phenomenon in terms of its own inherent system of meaning.”<sup>75</sup> For me, it appears that the practice of phenomenological epoche is to make explicit the emotions by journaling that cannot block all my

---

<sup>74</sup> Virginia Woolf, *A Room of One’s Own* (Boston: Mariner Books, 1989).

<sup>75</sup> Wikipedia, s.v. “Epoché,” [www.en.wikipedia.org/wiki/Epoché](http://www.en.wikipedia.org/wiki/Epoché).

biases and assumptions but more exactly involves the process of making explicit that I own these biases and assumptions. While practicing the phenomenological epoché, I recorded my feelings and tried to trace from where they originated by reflecting on my process of growth or my feelings toward my own family. It was mostly a fear.

Before I began an interview, I sensed in myself a hesitation to begin. I felt afraid to confront pain and heaviness. Through daily meditation and journal writing, I consistently tried to explore and confront that hesitation. I also waited until the last minute which shows the amount of hesitation I had to meet these mothers; I wanted to see what this fear looked like and, more importantly, to feel it completely. I needed to know what was happening to me, and why, in order to lessen any transference to the women I interviewed and to avoid misinterpreting the way I understood parents' voices. I figured that the heaviness and fear was *mine*; a fear about abnormality, being dismissed as invisible by the society, being left aside, being not noticed, experiencing shame, mourning the disability. It was *my* fear, not the parents'. I had not yet even met the parents! With this in mind, now I turn to introduce data collection.

## Data Collection

The data collection for narrative inquiry includes interviews, observations, documents, pictures, and other sources of qualitative data, such as artworks or blogs of mothers and their children.<sup>108</sup> Narrative inquiry enabled me to focus on and look deeply into mothers' narratives. It gave me an opportunity to look deeply into their worldviews. Mothers' narratives from the Zoom interviews became my major source of data. For this research project, I conducted four interviews, two with each parent. Each interview was about 60 minutes long and was held through Zoom. I intentionally scheduled a week in between interviews so I had enough time to

“delve”<sup>76</sup> into the data and also time to do some additional research; for example, to follow up with specific things that parents mentioned, in order to more deeply understand parents’ experiences. The Zoom interview was recorded with the permission of both research participants and was then transcribed by professionals. I use a transcribing service in order to minimize the potential barriers that I might have as a person who speaks English as a second language.

Before the interview, while I was communicating with them via email, I explained the interview procedure and sent the consent form in advance so that research participants would have adequate time to read it carefully. The consent form was signed at the beginning of the Zoom interview and was sent back to me via email. After the consent form was signed, I then addressed the possible risks and verbally confirmed some of the contents they had agreed to that were in the consent form. For example, two of my participants did not want to use a pseudonym but were open to use their real names. I confirmed that verbally.

In addition to using the interview as a major source of data to analyze, I used materials such as media representations, publications, and internet websites featuring these mothers that I had interviewed or their children. Artworks, also, became sources of data. As an established artist herself, Alice’s art appears to tell stories that I can’t relate here that support her narratives by providing details. For Karyn, I looked at her daughter, Corbyn’s writing, as a window into Corbyn’s inner world that eventually influenced Karyn’s emotions, including her poems she published in her blog. My research journal becomes a source as well in that they allow me to explore any insights that occurred to me and also to prevent possibilities of transference. I began writing a research journal to keep notes of my interior movements, especially to discern my

---

<sup>76</sup> Creswell and Poth, *Qualitative Inquiry*, 20–22.

prejudice or bias and to lessen the possibility of transference from the beginning. I kept a research journal after each interaction or interview with parents.

### Interview Structure

I employ semi-structured interviews. Interviews are designed to focus on parents' experiences and lived theologies. That is, I would ask about their experiences and their thoughts and concepts and how they came to construct those ideas. Two interviews were intentionally planned so that I could focus on one major question each day: What is disability? and What is each mother's understanding of the relationship between parents and children? With these two important questions set, I left room for other questions to follow the flow of the participants and for participants to determine the content of subsequent discussions. For each session, I also opened the possibility for a third interview so that I could invite the participant to answer any remaining questions I might have. I developed two sets of questions as I described below according to two themes on which my work is focused: disability theology and theology of care as below.

#### Part A - Disability Theology: Day 1

1. Would you tell me about yourself?
2. How do you identify your religion? How do you understand your spirituality or faith?
3. What has been your experience in raising a child with disability?
4. How was it to first face this awareness in this child?
5. What is your understanding of disability?

## Part B - Disability Theology: Day 2

1. What do you think is your role in relation to your child?
2. How have you responded to the challenges you experience in relation to your children? If you have coped with those, what has enabled you to cope with the challenges? (Deconstructive question)
3. Would you be able to describe your relationship with your child? (Relational frame from the narrative therapy- externalizing the problem)
4. What has been helpful in raising a child with disability?
5. What kinds of hope do you have for your child, if you have any?
6. How does raising a child with disabilities change, if it changes, your life?

These questions I came up with are rather broad, general and open-ended questions. Creswell made a point that when forming questions of research based on social constructivism, it is better for questions to be broad and general enough so that it can give a plenty of room for participants to construct their own meaning and also to have a chance to pay attention to the “processes” participants develop with their circumstance.<sup>77</sup> For social constructivism-based research, Creswell asserts that this process is integral as it is through the processes of interactions participants make meanings with things around their realities. Specifically, for this, I use the lens of “relationship” to uncover the process of interaction of mothers with their children and with the notion of disability.

Further, these interview questions are specifically designed and guided by a philosophy and principle of narrative therapy of externalizing the problem and deconstructive questioning.<sup>78</sup>

---

<sup>77</sup> Creswell and Poth, *Qualitative Inquiry*, 24.

<sup>78</sup> Goddard, Lehr, and Lapadat, “Parents of Children with Disabilities,” 277.

For example, as narrative therapy regards subjectivity important, I deliberately differentiate between the problem and the person throughout the interview, such as saying “the problem” instead of “your problem” or “your child’s problem.” This is, in narrative therapy, one of the necessary skills — to externalize the problem.<sup>79</sup> Through using this frame, throughout the interview, I intentionally make room for subjectivity and identity of mothers and to discover mothers’ relationship with the notion of disability. I generally try to make this spirit permeated over the course of the questions particularly, the idea is embedded in questions such as in Part B. 2 and 3.

---

<sup>79</sup> Goddard, Lehr, and Lapadat, “Parents of Children with Disabilities,” 277. I learned from this article how I can employ the skills of narrative therapy in interviews.

## Chapter 4

### **Mothers' Relationships with Their Children's Disabilities: Thick Description**

This chapter engages mostly in a descriptive task with elements of an interpretive task. It does this by exploring the narratives of the experiences of Alice and Karyn, two mothers of children with disabilities. Their stories begin before they had their children, they move forward to when each mother meets her child and discovers the child's disability. The stories then continue to the present. This chapter plays two roles in this dissertation.

The first role is that it offers "thick descriptions" of mothers' experiences pertinent to their construction of their lived theology. Gilbert Ryle, a British philosopher, created the term "thick description," which has been appropriated by Clifford Geertz, an American anthropologist.<sup>1</sup> Geertz proposes the usage of "thick description" as a way to understand culture. Geertz asserts that thick description is the most appropriate method to use in order to understand culture, because culture is fundamentally interpretative, and it is "in search of meaning."<sup>2</sup> In this regard, cultural activities are best understood as depicting daily lives, including meaningful symbols for people. According to Bonnie Miller-McLemore, "'Thick description' means seeking a multilayered analysis of human strife, including detailed, intricately woven, 'experience-near' rather than 'experience-distant' readings of the 'living human document.'"<sup>3</sup> Miller-McLemore

---

<sup>1</sup> Gilbert Ryle's term "thick description" means to see all the possible meanings of an action. Clifford Geertz, *The Interpretation of Cultures: Selected Essays* (New York: Basic Books, 1973), 312.

<sup>2</sup> Geertz, *Interpretation of Cultures*, 211–33.

<sup>3</sup> Bonnie J. Miller-McLemore, *Christian Theology in Practice: Discovering a Discipline* (Grand Rapids, MI: William B. Eerdmans, 2012), 45.



points out that “the methods of pastoral theology have demonstrated the value of ‘thick description’ as a powerful beginning point for all the fields of theological study.”<sup>4</sup>

As such, by providing thick descriptions of mothers’ day-to-day lives, I will explore what terms mother apply to their children’s disabilities and how mothers construct meaning for these terms in relation to their children’s disabilities. This directly relates to Richard Osmer’s understanding that the role of the descriptive task is to gather “information that helps us discern patterns and dynamics in particular episodes, situations, or contexts”<sup>5</sup> in order to answer the question of “What is going on?”<sup>6</sup> This chapter shows the specific patterns and dynamics of mothers’ lived experiences on which I will build to provide more explicit interpretive work in chapter 5, from which I will elicit normative value in chapter 6 and for which I will offer a constructive proposal in chapter 7. Although in practical theology descriptive work and interpretive work are described as two discreet movements in practical theology, they are intertwined in nature. Thus, in my dissertation, these two tasks are not separated. In this section, I describe women’s stories and I also present meanings that I can interpret. In this way, this descriptive and interpretive work is a collaborated work and in essence dialogical.

The second role is that while this thick description offers the experiences of mothers, it will also begin to reveal the gap mentioned in the current psychosocial and in theological literature that I have delineated in chapter 2. The narratives of Alice and Karyn, in this chapter, clearly show the areas that couldn’t be fully understood or addressed by the current theories, although, the more explicit analysis will take place in the next chapter. Specifically, Alice’s and Karyn’s emotions toward their children’s disabilities are not linearly processed in the way that

---

<sup>4</sup> Miller-McLemore, *Christian Theology in Practice*, 45.

<sup>5</sup> Osmer, *Practical Theology*, 4.

<sup>6</sup> This dissertation draws on the large structure of Richard Osmer’s four tasks. According to Osmer, the third task, the descriptive task, is ultimately to answer the question of what is going on.

Rosalyn Darling presents the process that parents of children with disabilities go through: anomic-seekership-advocacy.<sup>7</sup> There are many experiences and emotions mothers feel that resonate with Darling's model. However, what Darling misses is that the experiences mothers go through are not always in order. That is, for mothers, different emotions of sadness and joy or their attitudes of resistance or acceptance toward disability tend to coexist or overlap; one emotion does not completely replace another. Furthermore, mothers' understandings of disability are not limited to one nor are they consistent — and theological correctness is not the only element that influences mothers to hold onto specific theological understandings of disability. Rather their narratives reveal that different understandings of disability coexist. These differences will be more explicitly and deeply engaged in the following chapters.

This point—the role of “praxis functioning as a critical force to critique status quo knowledge and to be disclosive of theological value”—is described by Elaine Graham, a Practical Theologian who works as Grosvenor Research Professor at the University of Chester.<sup>8</sup> I interpret it as also consistent with Osmer's understanding, because in Osmer's four tasks related to the formula of practical theology, the goal of the first two tasks, the descriptive and interpretive, is ultimately to solve the problem.<sup>9</sup>

While providing the thick descriptions of Alice and Karyn, I also engage in the interpretive work. In doing so, I specifically use the narrative therapy approach which places mothers at the center of their narratives. I do this because mothers often center their children in their narrative just as their lives are oriented to their children's disabilities. Positioning mothers in the center of the narrative can be effectively done by applying the relational framework of

---

<sup>7</sup> Rosalyn Darling, *Families against Society*.

<sup>8</sup> Graham, *Transforming Practice*, 172–75.

<sup>9</sup> The last two tasks, normative and constructive, are explicitly to solve the problem.

narrative therapy: to place mothers into a center and explore what kinds of experience and/or relationship they have with their children's disabilities. While the narrative therapy approach is helpful in its focus on mothers' experiences of their children's disabilities, the thick description will also show some ambiguity: that for mothers it is difficult to think separately of their children and the disabilities. Which leads to a need to modify the narrative therapy in order to use it adequately for mothers of children with disabilities. This modification will take place in chapter 8 as a pragmatic task. With this structural understanding, I now proceed to my participants' stories.

### **Alice's Story**

Alice

The walls in most art galleries, especially those that display modern art, are white. That is because—for modern artists who are experimenting with new ways of seeing—“gallery spaces were adapted to suit the new ideas and materials being explored.”<sup>11</sup> From this perspective, “white was considered to be an effective means of creating a pure space; a void-like atmosphere, in which art could be experienced without distractions.”<sup>12</sup> The whiteness of these walls appears even more pale and austere when integrated with an art display featuring multiple needleless syringes. The array of syringes was connected vertically like a mobile from the wall (see figure 1). The lines of syringes appeared slender and malleable as if a person could easily reach out and bend them. Part of the syringes as well as the threads suspending them were painted bright hues of yellow, blue and red. These eye-catching colors added a sense of playfulness to the mobile, despite the perturbing subject matter. However, even with the playfulness, the mobile made of syringes produced an eerie display and I felt as though the mobile was asking questions of the

viewers: What do you think I am? Do I look like a syringe? Have you thought about those whose lives are surrounded by syringes like these? Do you know anything about these kinds of lives?



Figure 1. *Check Residuals* by Alice Marie Perreault, 2019, Claremont Graduate University Art Gallery, 2019.<sup>10</sup>

---

<sup>10</sup> Screenshots from “Check Residuals,” YouTube video, 1:17, 1:36, 1:12, uploaded by Perreault, April 6, 2019, <https://www.youtube.com/watch?v=TVL5U6qqabw>.

This was one of the recent works by Alice Marie Perreault that was presented at the Claremont Graduate University Art Gallery in 2019. Alice has been an artist her whole life. For some people, jobs are simply a means to earn a living. But for people like Alice, being an artist is at the core of her identity, since art has been the way she has communicated her life experiences. Though she received traditional artistic training, she identified herself as “absolutely not traditional at all, because I’m incorporating all the medical supplies. It’s about responding to the world I live in and what’s going on, and having that be brought into my art.” At this point, I was curious as to what “art” means for Alice since the definition of the term “art” varies from person to person. For Alice, being an artist is the ability to see things differently; to provide a new perspective. Having Julius and experiencing Julius’ disability has indeed provided her with a unique perspective and has become her source of artistic inspiration and has added a new identity of ‘advocate’ to Alice in addition to ‘artist.’

In 2019, Alice Marie Perreault—at age 47—was an established visual artist based in Southern California who graduated from Claremont Graduate University with a master’s degree in Fine Arts. In 2022, she is a single mother living in Claremont, California, and caring for her two children. One of them, Julius, is now twenty-three years old and uses a wheelchair to deal with his quadriplegic cerebral palsy.

Consequently, Julius’ mobility is almost totally assisted by and dependent on others’ care. His head is little bit tilted and on most of the occasions we met he was wearing a colorful bandana as a Covid pandemic mask. In our initial meeting, I learned that Julius is hardly able to speak, but he does make a repeated rumbling sound to notify a caregiver when fluids need to be suctioned from his mouth.

The gurgling rattle-like sound Julius makes is like background music that goes on 24/7 for Alice. Alice's daily life is inseparable from Julius's life; this is not a metaphor, but her day-to-day reality. At the beginning of the interview, she asked me "Can you hear me, okay? My son is making a gurgling sound." She then said directly to Julius, "You're getting noisy," before turning back to me to ask, "Alright, can you hear me okay?" During our interview, she had to excuse herself briefly several times. "Because I have to keep him suctioned, I will probably have to do that [again] in a few minutes." This interview with Alice allowed me to observe the visceral reality Alice is living in, the sound Julius constantly makes to signal his needs, and the reality of what it means to be a full-time caregiver to someone who requires around-the-clock care. Each time she left the interview, she returned within two minutes saying, "Just got him suctioned" I was struck by the degree of efficiency she demonstrated when attending to her son.

The fact that Alice needed to be with Julius to suction him— at least once in an hour — while I interviewed her, immediately raised the concern that these interruptions caused a high level of distractibility. But I became aware that the notion of 'distraction' was solely derived from my biased perspective, and soon I redirected the orientation of the concept of 'distractibility.' From whose perspective is it a distraction? Was Julius' need to be suctioned a distraction in an interview? Or was my interview a distraction to Julius' need to be suctioned? Perhaps this variability shows that neither his sounds nor the interview was a distraction.

I divide Alice's narrative, largely, into three parts. These parts are divided according to Alice's attitude toward general disability, her sister's disability and Julius' specific disability. In Part 1, I delineate Alice's relationship with disability before having Julius. Alice was familiar with the concept of disability because her older sister had Down syndrome. According to her, this prior experience wasn't a pleasant one. Part 2 begins with Julius' diagnosis. The prevalent

mood of part 2 is unexpectedness, shock, sadness and a deep sense of loss. I include three episodes that prominently reveal Alice's response. Alice's conversations—with the medical staff and another mother of a child with similar disability—display deep emotional distress as Alice begins to question her taken-for-granted notion about what it means to “sit.” Creating art begins to function as a coping mechanism for Alice because it allows her to process her feelings of pain and embarrassment, and her deep sense of loss. In this section, what is notable is seeing Alice as the recipient of Julius' diagnosis, where she presents her passive side as she faces an onslaught of new information. Although these feelings and attitudes were not fully resolved in Part 3, they undergo a significant change when Alice embraces her agency. While seeking therapies and treatments for Julius, Alice begins to find her own answer in regard to various notions of Julius' way of communication. Through this process, I also see that Alice's sense of identity has expanded to include Julius' disability.

As I delve into Alice's narrative, I also incorporate Alice's artwork, because it provides us with a medium to see her inner world and the method Alice employed to process her emotions, both of which result from the experience of raising Julius. My approach is similar to how I utilized her artwork in the beginning of this section. From a broader perspective, Alice's artwork contributes to setting the tone of the entire narrative and more directly it contributes to showing what she has experienced through her son's disability and how she has responded to it. With this basic information and initial impression, now I introduce Alice's story pre-Julius.

#### Pre-Julius

Alice was familiar with and knew what it meant to be part of a family that included a person with disability. Even before Alice had Julius, Alice was used to a role advocating for

people with disabilities because her older sister had Down syndrome. Because of this early exposure to disability, for Alice, disability was something to advocate for, something to explain further to those who would ask “What is wrong with your sister?” Alice never felt comfortable trying to make people understand why her sister had Down syndrome and many times, she felt a sense of dread when she faced this situation. Unfortunately, more often than not, people could not wrap their heads around her explanation, which would only prolong Alice’s uneasiness. This unresolved distress is repeated in part 2 when she faced her son’s disability.

Alice was becoming increasingly involved with the arts; she taught at three universities and put on art shows. She was afraid of the possibility of losing all of her achievements as an artist because of her disabled newborn baby. Even before she became pregnant, Alice thought it would be difficult to be an artist and a mother at the same time. Her fear brought her to the point that, before Julius’ birth, when a person called her “mom,” she wanted to “smack that person in the face.” However, to Alice’s surprise, after Julius was born and she was called “mom,” instead of wanting to “smack the person’s face,” she thought to herself, “Oh, I’m the mom.” It was now a pleasant and tender word that inspired a sense of home in her. It was at this point that Alice began to love being a mother.

### Facing Julius’ Disability

Even though Alice had already experienced and knew about disability through her older sister, what she experienced with her sister’s disability was on a different level than her son’s disability. The primary theme of this section of narrative is Alice’s deep sense of loss as she learned of Julius’ disability. Three related topics emerged from this main theme: 1) Alice’s response to Julius’ diagnosis, 2) A question posed by Grief and 3) Alice’s response to Julius’



disability through Art. While exploring each topic I will focus on Alice's "new" experiences with the doctors' diagnosis, Julius' disability, and phone conversations with another mother whose daughter had symptoms similar to those of her son. At this point, Alice is beginning to be exposed to various understandings and assumptions of disability through different people. In these episodes, Alice's reaction usually involves a level of intense shock, sadness, disappointment and fear. Perhaps, just like Alice had worried initially when she discovered that she was pregnant, she was experiencing transitional moments. However, these experiences turn into a transformational moment in an unexpected way. The existence of Julius and Julius' disability begin to offer Alice the new identity of "mother" and this identity also flows into Alice's professional-artistic identity. This leads to one of the important themes of Part 3, the expansion of Alice's identity. The narrative of Part 2 shows the beginning of this transition through the changes in Alice's art style, artistic themes, and tools. Before describing her art, let's explore her response when facing Julius' disability.

#### Alice's Response to Julius' Diagnosis

Julius was diagnosed with spastic quadriplegia cerebral palsy very soon after birth—within the first year of his life. Alice said it is usually rare to diagnose babies this early. As part of the diagnosis process, babies go through multiple tests that allow doctors to evaluate their physical and mental condition. Alice explains that there are certain patterns in the neurology of affected babies, including episodes in which they will experience seizures. Then, in more severe cases, other abnormal occurrences begin, and Julius followed that pattern.

In the beginning, Julius' disability was a distressing headache for Alice. It was difficult for Alice to understand what was going on with Julius and even more so to accept it. Alice literally could

not understand what was going on within her baby's body nor did she understand that his condition was not curable. "We have medicine and science," Alice said, assuming they could cure what was happening. After Alice heard Julius' diagnosis from the doctor she asked back, "What can I do?" and the doctor's answer was clear: "Nothing." Her subsequent feelings of helplessness were an insurmountable wall and the hurt she experienced after being told there was "nothing" she could do, endured for a long time. It was not only a matter of whether or not Julius could be cured, but also the doctor's unsympathetic, indelicate manner. Alice was shocked that the doctor could say "nothing" so insensitively in front of Julius! Julius could have heard this cold reply and lose all hope. What if Julius could have heard what the doctor had said and then thought that his life was practically over? Alice could not fathom the doctors' callousness toward Julius and herself. Twenty-one years later, in the talk show she had at USC Keck School of Medicine, she urged future doctors and clinicians to, "Never say there is nothing that can be done. Give hope of something parents could do—at least a little thing."<sup>11</sup> This, to some degree, indicates the level of emotional hurt and shock Alice experienced and its lasting effect until today.

During this time, as we can infer from Alice's immediate responses, disability, specifically Julius' disability, was something she felt had to be cured, a "thing" or "status" that had to be changed and fixed. However, in reality, this was far from the case. The gap between Alice's conception of Julius' disability and the response from the medical staff that there is nothing she could do, resulted in a deeply rooted pain that afflicted her for years. Alice recalled crying tears of frustration, desolation, hopelessness, and denial. She would keep thinking, "No,

---

<sup>11</sup> "Artist/Caregiver Alice Marie Perreault Discusses Her Chain-Reaction Exhibit at USC, Keck," Keck School of Medicine of USC, YouTube, <https://www.youtube.com/watch?v=ZhHUnlpNyQY>, accessed August 10, 2022.

he's gonna get better, he's gonna. . . . We have science, we have medicine, he's gonna get over this.'" It was a long time before she accepted the reality of Julius' condition. That said, acceptance did not mean Alice's emotional wounds were completely healed. She still felt pain at home every time she saw him not being able to hold his head up and at the hospital when she witnessed the tube going through his nose into his belly.

### Grief Poses a Question

Facing the sense of loss, grief posed a question to Alice that led her to begin to explore Julius' ways of communication and his abilities, instead of his lack thereof. At one point between taking him to the doctor and trying to fathom Julius' condition, Alice sought out comfort to help her cope with her loss of direction. Julius' pediatrician had referred her to another woman whose child had a condition like her son's. They had a phone conversation, but for Alice, it was not very helpful, nor did it provide her a sense of validation. On the contrary, it intensified the deep pain Alice held in her heart because she was unable to establish any sort of emotional connection. The other mother's child was already a few years old while Julius was still an infant. Alice called this woman and asked some basic questions, "the way any person would ask somebody who doesn't understand physical limitations." Alice questioned, "Does your daughter sit up?" The woman answered over the phone, "Oh yes, she can sit for about 20 seconds before she falls over." Although she had heard the words correctly, all Alice digested from this affirmative answer was, "No, she doesn't sit." Alice's emotions were racing as she thought to herself, "No, that doesn't count." With her stomach in knots, she continued the phone call and asked several more questions. Her face contorted as she recalled the answers as "devastating, they were just devastating." During this conversation, silent tears streamed down her face as she

tried to level her breathing so that the woman on the other end of the line would not know she was crying.

Alice explained,

Because she was so happy for all the things her daughter could do, and I didn't see that [as] the girl [being able to] do anything. I only saw it as what she couldn't do – she could only sit for 20 seconds! Does that count? And what happens if you get to a place where you redefine ... What does sit mean? You [have to] redefine things, right? You redefine what is "talking". What does "communication" mean?

Re-examining common notions, for Alice, in a way that fits and make sense of Julius was Alice's own process of understanding Julius' disability. The grief, sense of loss Alice experienced was posing a question for Alice that required new terminologies. These early experiences of confronting and dealing with Julius' disability allowed Alice's art to turn in a new direction; it became a source of inspiration for a work she created when she went back to graduate school a few years later.

#### Alice's Responded to Julius' Disability through Art

Prior to Julius's birth, Alice had committed herself to featuring her art in a show, and she already had outlined specific ideas for the show. However, she was sidetracked after Julius was born due to the unexpected disability Julius come with. She could no longer work on her original concept because she could not relate to the work anymore. Alice found herself derailed from the path she had envisioned and found herself in uncharted waters. All she could think about was Julius and Julius' disability. She expressed her concern: "Now that I was in the throes of this, how could I [even] show that other work? How could I talk about it? That didn't work. The body didn't work the way that I thought it did. Communication and relationships weren't what I thought they were, so all that work became obsolete. So I started a whole new set of work."

We know from Part 1 that her expertise lay in portraying the human figure. She was conventionally educated as an artist and taught figure drawing based on traditional principles of anatomy and movement. However, Julius' disability directly challenged the knowledge and conceptions she had about the human body. Alice divulged her concern,

I had to take a lot of time to get down the neurology of a new baby that I couldn't understand. I had to get a medical dictionary, I had to go to the medical library [since] we didn't have internet. I was trying to figure out and understand what happened to my baby. I needed to know internally what happened to him. I tried talking to other parents and I was very surprised that they couldn't tell me either. These were parents who were in similar situations. They couldn't tell me, medically, what happened — and I needed to know.

Her artwork titled "Buddy" (see figure 2) presents the struggle and ideas Alice had around this time. When I first saw Buddy and accompanying images, I thought of it as a consolatory series of pieces that convey a sense of deep reflection amidst tumultuous emotional experiences. Buddy, Alice explains,

Is a medical tool... what happens to Buddy will happen to 'the child'; so I see Buddy as a modern-day voodoo doll. Each time that he went into the hospital, Buddy came with us... all the procedures that my son was going to get would happen to Buddy first and then to my son. So Buddy became a surrogate, so to speak, and when the child was taken away from the parent and brought into the OR, Buddy was passed to the parent and then the parent held Buddy instead of the child; so there's a lot of connection with Buddy.

"Buddy" is a series of dolls featuring many different skin tones that are made by volunteers to comfort parents of sick babies when the babies are taken from parents for treatment. The face of the doll is blank so that a child can draw a face on it. Alice embroidered Julius' portrait on the face of the doll while she was sitting by Julius' bedside. While holding and playing around with Buddy, Alice began to imagine what if Buddy were Batman? What if Buddy could change into a different person? And thus, the series of Buddy figures became the art project Alice took on to provide herself with solace.



Figure 2. *Buddy* by Alice Marie Perreault, 2014.<sup>12</sup>

### Looking for Therapies, Yearning for a Cure

In the previous section, we primarily see Alice's shock emerging in response to external factors such as the doctor's diagnosis and her conversation with another mother. The initial set of intense emotions that Alice felt remained—pain, sadness, loss, frustration; however things take a turn for the better. As we will see in this episode, Alice no longer stays in the passive position of someone who responds to the situation she faces as we saw in Part 2. She becomes more active in seeking treatment and therapeutic interventions for Julius and even musters the courage to step into a leadership position in providing creative-caring space for children with disabilities. Her newfound confidence allows Alice to assume a protective stance for her son, to shield him from the ignorance found outside of the world she builds for him. Additionally, Alice begins to try to see and understand Julius in his own light. Through learning the inner mechanisms of Julius' world, his way of interacting and communicating, Alice undergoes an expansion of her world.

---

<sup>12</sup> "Alice Marie Perreault," Alice Marie Perreault, accessed December 14, 2021, <https://www.alicemarieperreault.com/buddy.html>.

By engaging in this enlightening process, Alice experiences Julius' disability and dependency in such a way that allows them to be included in her sense of identity. This is evident in her artwork. That said, while Alice faced an illuminating expansion of her identity, she also had to endure conflicts with the people at school and at church who did not understand her.

### Endless Waiting

Alice never expected that she would one day become deeply immersed in the medical world and fluent in its jargon. It definitely did not come naturally for her when she tried to learn and grasp complex medical terminology and concepts. When she was first learning about Julius' condition, she read a lot of medical journals. "I understood them completely inaccurately," she chuckles. Nevertheless, with time and effort, and fueled by desperation, Alice soon became quite knowledgeable about her son's disability. She "really wanted [to uncover] a cure...so badly," and tried every single form of therapy she could find such as Feldenkrais therapy, Reiki therapy, sacral therapy, Craniosacral therapy, and hypnotherapy. Alice's exploration of therapies led her to some she had never heard of, let alone imagined.

Part of the reason why Alice did her own research on interventions and had Julius receive multiple forms of therapy was because there were no official medical measures or holistic treatments available for Julius. When Julius had received diagnosis, the doctors told Alice that they anticipated that "help would be available within the decade for those with brain injuries like [her] son's and other neurological disorders."<sup>14</sup> This was 20 years ago. This poor prognosis left Alice scrambling to clutch onto her hope while it unraveled right in front of her. After 20 years, "Yellow Sweater" was Alice's artistic response to this fraying hope—which indicates the prolonged hope Alice had to cling to. Alice explains this frustration.

I had no idea. It's really interesting 'cause you can't see that far ahead... When you have your baby, you just see a baby and you're like 'oh, this is gonna [be okay]. . . . We can get through this and there'll be a cure.'" And next thing you know, he weighs as much as you do and you're still doing the same thing, but it's a lot harder physically... he fell out of the bed the other day. Oh God. He split his chin. I was so upset. And then he has to be fed, and here's his tube, his syringes.

Despite this fraying hope and sense of frustration, Alice forced herself to believe that there will be a better future for Julius. This practice and belief were materialized into an artwork called, *Yellow Sweater*. As we can see below in the picture it does not seem like a yellow sweater at all; however, it is indeed a yellow sweater for Alice because, she explains, "if I say 'this is a yellow sweater' repeatedly, I will eventually believe it." Putting a trust on a dream or a plan that is necessary for her own child is devastating. It is because while desperately needing a cure, a person swings between trust and uncertainty. The *Yellow Sweater*, according to Alice's explanation, indicates a level of frustration, hopelessness and sense of being overwhelmed.



Figure 3. "Yellow Sweater" by Alice Marie Perreault, 2019.<sup>13</sup>

### Facing the Same Question with a Different Response

We know from Part 1 that Alice had experienced embarrassment as a child when she had been asked, "What's wrong with your sister?" In this episode, we will see Alice being asked that

---

<sup>13</sup> "Alice Marie Perreault: Visual Narratives," Alice Marie Perreault, accessed December 14, 2022, <https://www.alicemarieperreault.com/overview.html>.



question, yet this time, it is directed at her son. Alice felt the same sense of dread and unpleasantness she had felt back then. However, I want to highlight how Alice had learned to respond to it this time around – this time, she was able to think, decide, and take action assertively. Perhaps, this resolve came from her earlier intimidation and anxiety from the prospect of being asked this question when Julius was still a baby.

At that time, Alice was terrified that other people would recognize Julius' disability, for reasons she could not put into words. When Julius was little, nobody recognized that Julius was disabled. Julius looked "just like a normal kid," Alice states adding after a beat, "I hate this word." When Julius was little, he was "a beautiful, beautiful baby." People would pause their conversations when Alice walked by with Julius in his stroller. When they glanced down at him they would gush, "My gosh, what a beautiful baby." All babies start out only lying down just like Julius did. However, most babies gradually learn to sit, crawl, walk, and eventually run. This, Julius could not manage to do; Julius could not move his body of his own accord. As time went by, Alice thought, "Oh my gosh, there's going to come a time," and knew that Julius' disability would eventually become recognizable. Slowly but surely, as Julius grew older, it became apparent physically, he "was not like a normal boy" because he could not hold his head up and could not stop himself from drooling. Trepidation filled Alice as she feared the day when the world would notice that her boy was not 'normal' because she profoundly cherished that time when everybody just thought he was as beautiful as she did.

Soon enough, the clock ran out and the time Alice had spent so many sleepless nights worrying about finally came. She was carrying Julius in a sling over her shoulder, even though he was already quite large. Someone asked, "Oh, can I see the baby?" Carefully, she pulled the sling down for the stranger to catch a glimpse of Julius before hearing those provoking words:

“Oh, it’s a big kid.” That sentence set off a flurry of apprehension and dismay in Alice. She quickly covered him back up and nervously said to herself, “Oh man, it’s happening. They’re starting to realize.” Then, on another day, Alice had Julius in the shopping cart at the grocery store, and the cashier was ringing up her groceries. Alice and Julius were both so happy and having a great day. She recalls, “Julius was smiling and looking around at everybody, and just . . . But he was lying down, he wasn’t physically moving. Only his eyes and face were moving.” The cashier suddenly glanced over and imprudently asked, “What’s wrong with him?” It was an all-too-familiar question and that still evoked an all-too-familiar sense of dread. Initially, she thought, “I’m gonna get that,” because she had already heard it many times when she was with her sister. “We’re so quick to make those judgments that if you’re not like me, then there’s something wrong with you,” she concedes. As much as she wanted to confront it, Alice decided to hold her tongue because she worried that her son Julius would hear the conversation and might think, “Oh, something is wrong with me.” She never wanted Julius to ever think anything was wrong with him, she wanted him to see himself as whole in the way he was. Thus, after being asked the question that she had been dreading for years, Alice smiled at Julius before looking back at the other woman before easily answering, “Nothing, we’re having a great day.”

The reason why Alice answered as such is because Alice felt like Julius was staring at her and he asked: “Is something wrong with me?” Alice had found that Julius was very conscious of everything she said, and she was confident that Julius was very much aware of what the pointed question meant. She notes, “It was a moment for me to be there for him. So I could have gone into the whole thing about his disability and what happened at birth and all... But that’s not what that was about. That was about me making my son understand that there’s never anything wrong with him, even though his body and his life and his way of interacting with the...,” Alice paused

for a few seconds to find the right sentiment before continuing. Nodding, she firmly stated, “His interaction with the world is different from ours, but it’s not wrong.” Although Alice faces the same questions that she is used to hear, this time, Alice resisted the impulse she had to offer counterpoint to the cashier but was extremely conscious about the effect the words would have on Julius. Alice made decision and acted upon it deeply considerate of Julius. It is also one of the moments when Alice begins to figure out an outstanding different way of interacting with Julius.

## Therapy

Alice was overwhelmed by everything new regarding Julius’ disability but at one point, she steeled herself and looked for help, through therapy, to help Julius and better understand him. At first, Alice did not know what she was doing and was completely naive when it came to accurately discerning which therapies were authentic. She initially found that there was a package called “basic therapies” that were a part of the insurance plan Julius was on. At this point, a case worker who had been assigned to care for Julius declared, “Okay, he’s gonna need speech therapy, he’s gonna need occupational therapy, and he’s gonna need physical therapy.” These different therapies would be provided to Julius at home under the program called “Early Childhood Intervention.” “These are [just] the basics,” Alice noted. Then, she learned that there are alternative therapies, such as Feldenkrais therapy, Reiki therapy, sacral therapy, Craniosacral therapy, hypnotherapy, and acupuncture. Alice tried almost every one of the alternative therapies with Julius. Some of them, like craniosacral therapy, appeared to work and Alice saw the results with her own eyes. In a craniosacral session, Julius was screaming nonstop. “It was horrible,” Alice recalls, frowning as she recalls this stressful experience. But soon after [the therapist started carefully and gently massaging his head,] Julius relaxed like jello and fell asleep. She

could hardly believe her eyes. Moments of success or respite such as these led Alice to believe in the power of alternative therapies. Among the ones she continued, Alice used acupuncture for many years, up until about two years ago. She figured that these were false claims but still noted that, “You [always] have to be really careful.” After enrolling in several therapy sessions, Alice began receiving messages from countless people who contacted her, asking her to send them money, and they would heal Julius from a distance using “brain waves” or spirituality. She stopped using these therapies and massages because she realized that once beginning a certain therapy, a person could easily get caught up in it and fail to notice any warning signs.

#### Developing Skills to Understand Julius

Alice began to learn that conventions that apply to other people do not necessarily apply to Julius and thus, began to rebuild these ideas in a way that could serve Julius. Insights came to Alice in a way that gave her an ability to articulate that she had not had before. One of the recognitions was about the term “spastic.” Before Julius appeared in Alice’s life, the meaning of spastic was simply how it was normally used in daily life. It was used to describe someone acting crazy and out of control. It generally applied to people who were being weird, goofy, upset, and “all that stuff.” I think Alice meant a behavior that is generally considered extreme or abnormally odd. However, while doing research for Julius, she realized the real meaning of the term: “spastic” means tight. Alice realized Julius was medically spastic because he has tight cerebral palsy. It was then that she realized why Julius’ muscles were constantly firing, and subsequently, why he was exhausted so often.

Realizing that the terms she had once used thoughtlessly have different medical and everyday meanings, Alice became hyperaware about the gaps in her speech and how it could be

interpreted. She notes that it was a stressful experience, “I’ll say something, and I’ll forget to define what that means to somebody, and then later I’ll think, ‘Oh no, they think I meant something different,’ because we have a different meaning for the same words.” These insights were painful for Alice to assimilate, because to some degree they confirmed Alice and Julius’ social remoteness. Realizing that her words were bound to be misinterpreted and misconstrued amplified their social experiences of being excluded from others and of being placed in a category that was deemed unwelcome – like spastic and out of control. However, Alice came to realize that not all deviations from conventional communication were harmful.

After much trial-and-error, Alice discovered and developed her own way to listen to Julius in a way that was different from the traditional way of listening. She had had embark on the reflective journey to redefine what ‘talking’ means. After all, Julius was not speaking. Alice broke down and cried and thought she would never hear the words, ‘I love you,’ come from him. In the beginning, Alice recalled Julius saying one word, “em.” Alice took that word to be Julius’ name for her. However, too soon afterward, Julius got his tracheotomy tube (trach) and lost even that small ability. Nevertheless, now, to Alice, Julius talks to her all the time, just without words. For instance, Alice has not forgotten the very first time Julius talked to her without words. Alice had a fond look in her eyes as she shared this impactful memory with me:

He was very specific about it, and he gave me a look that was not like any other look, right in the eye, very clear, very strong. And I just knew that that’s what he was saying. And I said, ‘Oh my goodness,’ I said, ‘I love you too.’ And then he smiled, and it was very clear that we were saying the same thing. He was just saying it without words. And he just did it again the other night, and he wouldn’t take his eyes off me, and I was busy, I’m working on him, I’m getting him hooked up to his machine and for his vest treatment and all that, and I am just a busy body, and he’s not taking his eyes off my eyes wherever I go.

Alice began to believe that Julius is not, as other people have said, unable to talk; Julius does talk, Alice retorts, “He talks a lot, but he doesn’t talk the way you talk.”

As she made progress with her son, Alice began to feel guilty because of the fact that she was gaining new insights out of her son's disability. Sighing Alice remarked, "There's guilt involved with that, right? Because it's the child's challenges that have brought you all these gifts. And so that's hard to live with, you know? It's hard to live with the fact that he has [his disability] and... [that] so much has been sacrificed in his life for me to have these gifts. Although so much has been sacrificed in my life as well. Right?" Alice's perception of her own self-imposed guilt reveals a deeply seated perception of Julius' disability as a challenge.

### Julius' Dependency and Alice's Identity

While Alice struggled to understand and find treatment for Julius, the things she experienced through Julius and from Julius became important parts of her identity. Alice's identity was expanded with Julius' dependency and disability, first and foremost, because being a mother of a child with disability granted her a strong connection with her son. Alice began to feel that Julius was an extension of herself. She began to think in ways that were framed by Julius' level of absolute dependency. After a while—and as a result of attending to Julius' absolute dependency—Alice inevitably began to perceive herself as an extension of her son. In Alice's words, "his entire world depends on me... From the time he wakes up even throughout the night, he's on a machine," that she must monitor and look after. From Alice's perspective, Julius' world operates only because he can depend on Alice. Julius, in order to access anything, needs Alice or someone who could act in her stead like a nurse.

Julius' dependency was one of the major reasons why Alice began to perceive Julius as an extension of her body. Alice felt that Julius' body and her body "are like one body." She noted, "I feel like my body is an extension of his body because his body depends on my body for

everything, and then I care for his body as if it's my own body." Such a perception reoriented Alice's entire day. The first thing Alice does is to take care of Julius. Alice would see Julius in the same position she left him the last time she provided him with care. Julius is hooked up to a machine that monitors his oxygen and his heart rate from the comfort of his own room. Alice set up a camera so she can watch remotely and respond quickly in the event of an emergency. When he gets uncomfortable, Julius will make a certain sound and Alice is always quick to react. After Alice gives her usual morning greeting such as, "Good morning, Buddy. How's it going? Did you have good dreams? What are we doing?" She then launches into the whole routine of getting him cleaned and bathed, and shaved— "Now he's a man, he has to be shaved. Oh my gosh, who knew I'd ever be shaving him?" Alice chuckled. This was only the beginning. Alice has to feed Julius—normally three times a day, but ever since Covid-19 forced his at-home nursing care to discontinue, every one of his needs had to be met by Alice alone, which has made three meals all the more difficult. To manage her workload, Alice reorganized Julius' meals into two feedings a day upscaling the portions she feeds him twice a day. Despite the daunting lengths she goes through, just in a morning alone, Alice tries to always be positive to model optimism for her son. To others, this devotion may seem unfathomable, but it was how Alice fostered her invaluable connection with her son.

This sense of connection to Julius that Alice experiences was hardly understood by others. Alice's experience at a Catholic church in Utah not only fortified Alice's sense of being connected in her body with Julius, but also demonstrated people's misperception or ignorance of Alice's emotions.<sup>14</sup> At a Catholic church, the priest tried to give Communion to Julius. Alice stopped the priest because Julius was physically unable to accept it. After passing Julius, the

---

<sup>14</sup> This is interesting because she said she feels she is separate from her daughter, who doesn't have a disability, but feels very connected with Julius.

priest tried to give it Alice. “No, no,” Alice immediately said before firmly stating, “No. If you can’t give it to him, you can’t give it to me because we’re one, do you see?” Alice was not sure the priest understood this and noted,

It’s very difficult for people to understand that sensibility and that my role is an extension of his body, whatever he needs is going to be my responsibility, whatever his body needs, whatever his mind needs, whatever. It’s a big role. In the beginning I was terrified because I thought—and it’s still there but you learn how to live with it—if I make a mistake, he could die. I think that’s a pretty phenomenal thing for physicians to have to understand and live with, if you go into care, if you go into medical care.

Part of the reason why Alice came to have such a strong sense of ‘one body’ with Julius is that, while caring for Julius, Alice realized that Julius’ condition was totally up to Alice.

Alice’s most minor action can affect Julius’ well-being in a significant way.

However, Alice was frustrated when people around her did not seem to understand this notion.

Even when she was in graduate school at Claremont, the artworks she produced were mostly about her son. For this, she was criticized and reproached. Her professor often chided her, claiming that what she created was not about herself. Alice simply could not make sense of these critiques because to her, the artworks were indeed about herself. Just as Julius wholly depends on Alice for his care, Alice’s world revolves around Julius. There was no way Alice could begin to identify herself without talking about Julius. The works were indeed about her: “The art was about us.”

While Alice felt her sense of identity expand by including Julius’ dependency and disability, she experienced two different social understandings of herself. One of her realities is herself as an established artist and the other as a mother of a child with disabilities. She experienced being recognized for her ability as an artist but also experienced discrimination and prejudice due to her son’s disability, especially after she moved from Utah to Southern California. Alice was an established artist and teacher in Utah, and when she moved to



California, she was a student in a master's degree program for fine art. Alice said that when she moved to California, she experienced culture shock because she was not allowed to be with her son in the classroom. Her son was regarded as a "distraction" especially in the contexts to which Alice brings Julius. Alice soon felt she was judged because she had a child with disability. She began to question why women could not be both mothers and professionals. Alice had always dreamed of being both a mother and a professional and was determined to pursue both paths. When she had her second child, she hid it for a time because she did not know how it would be regarded at school. She recalled the moments when people could not make sense of her or her decisions: 'How is she doing this?' 'What does she think she's doing?' Alice felt that most people were unable to even begin to apprehend what she was going through. She turned these feelings of isolation into an art piece for a class. When she could no longer hide her pregnancy, she coordinated and prepared a performance piece to reveal it. Then, she served breast milk at one of the receptions. This experience was for her, "to make it real...[and] make a big deal about it."

Still, Alice understood these series of experiences and accomplishments as "being underestimated, incredibly underestimated" due to having a child with a disability. She recalled that prior to all this she "was ahead of her class in all ways, the recipient of a cash award at the end, receiving enough money to put a down payment on a house." This was the first time in her life, in an academic, fine art scope, that she did not receive acknowledgement for her excellent art. Before this, her treatment had been based on her talent and drive, but now she perceived that behavior toward her was based on the fact that she had a child with a disability. Alice held that, "I was judged in a very different way. So the people who knew me in Utah, who knew who I was before I had a child and knew how I handled it after, they had such high regard for me and never

hesitated to give me an assignment.” Yet, in California, where no one had witnessed her journey toward understanding, her reconciliation of her life before and after Julius was born, or her personal growth, she was reduced to a *persona non grata* whom people did not understand. So far, we have seen the influence of Julius’ disability in Alice’s self-understanding. Alice incorporated Julius’ disability into her own identity and this new self-identity couldn’t be understood nor affirmed by people around her.

## Hope

Alice has two foremost hopes. Those are “improving communication skills and mobility.” These two hopes are for Julius. Alice, when expressing her hope uses, “our” as a subject, once again affirming that her sense of identity is inextricable from Julius. She asserts, “Our biggest hope right now is for Julius to master [those] two things.” Alice smiles proudly as she explains that Julius recently began working with an eye gaze communication device in order to enhance his ability to communicate with people. She wants people to understand Julius as a person and for him to know that he is being understood. This hope came out of Alice’s experiences of witnessing people underestimate Julius’ intelligence and comprehension abilities. People’s failure to recognize their own ignorance were especially evident when they talked around him as if Julius was not there. Hence, Alice thought it would make an invaluable difference if Julius would be able to communicate; “to be able to communicate changes everything. If you have a method of communication, it changes your relationship with the world...So that’s a big hope for us.” Their other goal about the mobility was more abstract and went mostly unexplained by Alice. According to her, these two hopes are possible given the current technology. She contemplated her answer before saying that she wanted to add one more

that she knows is not necessarily possible given the current technology. Regardless, Alice continues to say that it would be great if there were a technology to help people swallow when the associated muscles are incapacitated or dysfunctional.

## Resources

For Alice, “the art studio made everything possible,” for herself and for other families. In 2002, Alice founded an art studio called “Kindred Spirits” in Salt Lake City, Utah which she directed until 2011 when she moved to Southern California. The Kindred Spirits studio was created with financial support from the Utah Arts Council, Salt Lake City Arts, and other private donors. The studio space was designed to be “an accessible, independent working studio with adapted tools and equipment to accommodate a wide range of abilities.”<sup>15</sup> Alice collaborated with local artists to teach quality art education to diverse groups of participants, bridging the gap between families living with disabilities and families living without disabilities. Participants engaged in hands-on experiences while learning about a multitude of art genres and cultures including the Arts of Mexico, Pop-Up Book Making, Japanese Brush Painting, Modified Printmaking, 20<sup>th</sup> Century Painting, Utilitarian Objects, Puppetry, African Drumming, Doll Making, Aboriginal Art and more. Children and adults were not separated by ages or abilities. There was a one-to-one ratio between student artists and their apprentices and, “Each worked at his or her own pace and no two pieces of artwork looked alike.” In 2008, as a result of her dedication toward art and inclusivity, Alice was honored with the governor’s Leadership Award in the Arts.

---

<sup>15</sup> “KS Studio—Kindred Spirits,” Alice Marie Perreault, Last Accessed December 14, 2022. <https://www.alicemarieperreault.com/ks-studio.html>.

Through the art studio, Alice was able to create her own reality where ability and disability were defined anew. Through the medium of art, Alice saw people through the eyes of those “differently-abled” and realized her new perspectives in her studio. In the next chapter, we will be able to see more closely the operation of the art studio from the perspective of an identity model of disability. For now, it is important to note that the creation of the art studio was one of the ways Alice responded to Julius’ disability and the way Julius’ disability was perceived in society. Organizing and overseeing the art studio not only made it possible for Alice to formulate her own conception of disability, but also functioned as a source of support for Alice to sustain herself. Furthermore, the art studio offered a real sense of dynamic community, a place of belonging for Alice and other families by connecting those who share similar experiences and views. However, the art studio was more than four walls that offered a sense of belonging. It was a space where Alice could create a new reality where different levels of ability are recognized and used creatively as well as a haven where children with disabilities and those without could coexist and play in peace. Their art was the medium that bridged the lives and existence of those willing to extend a hand toward those different from themselves.

### **Karyn’s Story**

Karyn

Karyn is a fifty-three-year-old woman (2022), a speech language pathologist, and the newly appointed Section Chief for the Speech Pathology Department at the Tempa Veterans’ Administration Hospital in Florida, USA. She is also an animal lover, a wife, and the mother of two children, one of whom has a disability: Corbyn, who was diagnosed with Down syndrome at three months old and is now thirty-two. In telling Karyn’s story, I will incorporate newspaper

called the *Tribune* which feature Corbyn and Karyn. Karyn's narrative will consist of the four topics beginning with part 1 when Karyn began to notice something was not right with Corbyn, the period until Corbyn got her diagnosis, and the way Karyn responded to it (i.e., mostly seeking out and having Corbyn receive therapies). In this stage, right before Corbyn's pivotal cerebral aneurism rupture took place, Karyn was in tension with her mother and doctors regarding Corbyn's physical condition. The primary objective in the first phase, was to pinpoint Corbyn's state accurately. I will then delve into Part 2 the moment when Karyn faced Corbyn's disability honestly. Here, it is important that the event made a significant emotional impact on Karyn, a traumatic experience that has lasted for a long time. In Part 3, after Karyn identified Corbyn's disability, Karyn was at odds with Corbyn's 'disability.' Now, Karyn had a new objective: to remove and/or minimize the influence of Corbyn's disability. Part 4's main idea of the last section of narrative is that Karyn, after meeting with a myriad of therapists, decided to become one herself. The objective in this episode is a continuation of the previous one: to fix Corbyn's disability. In this section of narrative, Karyn clashes with Corbyn, Corbyn's disability, and Corbyn's school system. Another notable topic in this section is the sadness and disappointment Karyn experiences through, and at times, alongside Corbyn. Throughout the narrative, we will see how Karyn had responded to Corbyn's disability. In the first section it was a relational conflict, then, in the second section it became a traumatic experience. In the third and last section transformation takes place and we will also see Karyn's sense of confidence grows and flourishes as she takes on a role that would allow her to devote herself to Corbyn.

I met Karyn through a third person who connected me with her via an email list. A person in the Community of Disability Studies saw my email seeking parents who are willing to do an interview, and connected me to Karyn.

At the very beginning of the first interview, Karyn asked me whether she could do cycling during the interview, to which I responded, yes. However, within 5 minutes of the beginning of the interview, she got off from the cycling machine and focused on telling her story. My first impression of Karyn was that she was confident and driven. I felt that the way she spoke was definite and clear. The look in her eyes cemented my first impression of her as “confident, assertive but not to the degree of being aggressive.” We began the interview with me leading our self-introductions. After she introduced her occupation, which was as a speech language pathologist and the new section chief for the department in the hospital, she added, “I became a speech pathologist after all of the issues with my daughter.”

“All of the issues with her daughter” began when Karyn’s daughter, Corbyn, was three months old and Karyn was an 18-year-old college student. However, before we delve into “all the issues with her daughter,” let me introduce her so that we can comprehend who she was before facing her daughter’s disability. Karyn grew up in an upper middle-class family. Her father was a doctor of internal medicine who had recently attained the title of vice president at his hospital. She was her mother’s first daughter and her father’s second. Her father remarried after falling in love with Karyn’s mother and stayed in the marriage until he died. Karyn has a total 3 siblings: one older brother, two younger sisters, all of whom are medical doctors. Both of Karyn’s parents were of Jewish heritage<sup>16</sup> and were forced by their parents to have a bat mitzvah or a bar mitzvah.<sup>17</sup> They had both resented their parents for this and decided they would not do the same with their children. Hence, Karyn had the freedom to choose her own religion and had experiences with both Christianity and Judaism, but did not actively participate in any religion. Karyn’s family would perform rites associated with the Jewish faith, like celebrate Hannukah and visit other Jewish people’s homes for Passover. However, they also celebrated Christmas

with a Christmas tree, on which they put ornaments and then gave each other a present to demonstrate love and affection. The celebration had nothing to do with Jesus's birthday, all that mattered was the family gathering. As for her parents' religion, Karyn recalls, "My mother believes in nothing, my father had some sense of something greater, something cosmic, something that might have some kind of overall power."

Karyn grew up to be a smart and easily bored young adult. She went to high school for just three years because it was too easy. She then went on to college thinking that it might challenge her but, as it turned out, it really did not live up to her expectations. She felt bored all the time. Just like everyone in her family, she thought she would be a doctor, but she did not have any drive to do so. There was a moment when she thought, "Well, if I have a kid that might give me motivation," but this was just one of those fleeting, noncommittal thoughts. During this time, Karyn was seeing someone, a person whom she calls her "sperm donor." She had grown up with this person but knew that this was not a person with whom she wanted to spend the rest of her life. Karyn had only one experience with sex before she got pregnant with Corbyn. "It wasn't on purpose" Karyn said definitely.<sup>18</sup>

Karyn's encounter with disability began with 'a strange feeling' when Corbyn was born. As Karyn told me that she neither knew or saw any kinds of disability before Corbyn. It appears that, for Karyn, the notion of disability can hardly be distinguished from her idea of her relationship with her daughter. Yet—as we will see throughout the narrative—Karyn put her entire heart and soul into minimizing the drawbacks of Corbyn's disability.

Before Karyn had Corbyn, she had no opportunities to experience or come to know about disability directly, unlike Alice, who knew and experienced one form of disability through her sister who had Down syndrome. Karyn was familiar with other kinds of diversity, such as race

and culture. Even so, before Corbyn was born, she had never given any thought to what it meant for someone to live with a disability. Thus, when she first heard doctors saying that Corbyn would need therapy, Karyn had to ask, “What’s therapy?” She tensed as she recalls the confusion she felt, “I knew nothing about it at all, and just had to listen to the doctors.” Her father had a specialty in endocrinology, so Karyn had heard about people needing therapy in passing to recover from accidents. However, she had never personally known anybody who needed any kind of therapy; she had never gone to school with anyone with a disability. Karyn smiled while talking about her experiences attending school with “embassy kids” whose parents were foreign diplomats or dignitaries. By interacting with peers from all over the world, she was exposed to and comfortable with people of all different races, cultures, and skin tones.

### Beginning to Feel Something Strange

Before Karyn’s encounter with Corbyn’s disability, Karyn began to notice something strange. Karyn’s early process of seeking to understand what was going on with Corbyn consisted of a number of relational conflicts. In the beginning there was no one in her family who trusted Karyn’s intuition about her daughter. Then it was the medical staffs who were able to confirm her instincts about her daughter. Divergent ideas about Corbyn’s physical condition caused a string of relational conflicts for Karyn with her mother and doctors and I see this phase as where Karyn began to sense her own voice and feeling that grounded her to take a more active role in later stages.

Not long after Corbyn was born, Karyn began to sense that something was not “right” with Corbyn. However, Karyn’s mother did not have confidence in Karyn’s attunement to her own daughter. Whenever she had that unsettled feeling, she would tell her mother, “I think the



baby's retarded or something." Her mother would callously answer, "You're retarded, she's *not* retarded, why do you think that?" Karyn could not find a clear answer as she could not rationalize her 'own gut feeling': "I don't know. I have a sense that the child has something wrong with her." "You are crazy" was the consistent, dismissive response she would get from her mother. It was not only Karyn's mother who completely disregarded Karyn's intuition about her own daughter. The doctors tasked with taking care of her and her daughter brushed off Karyn's explanations of bodily experiences and failed to take her concerns about her daughter's condition seriously. This lack of validation led Karyn to make multiple trips to different clinics and doctors. When that "strange sense grew," she began to take her daughter to see a doctor more frequently, with a greater sense of urgency. In my previous research, I observed several mothers' experience a similar pattern of conflicts such as Karyn experienced with medical staffs. It appears that since mothers are usually the closest person who takes care of their children, they are likely to sense 'something' before clear medical symptoms are observed. Usually in this case, they begin to take actions to confirm their hunch. At the time, her father was vice president and executive dean of the University of South Florida's medical school. For this reason, Karyn said, "I wasn't just Karyn. I was Dr. Gaufman's daughter." She acknowledged that her status granted her a level of privilege and that she had an advantage in being able access medical personnel and, thereby, services.

Despite being well connected, Karyn was still coming up empty when searching for someone to validate her concerns of "something serious being wrong with Corbyn," but she was relentless. "I knew there was something wrong with her, but of course, I didn't know what it was," she recalled, frustration etched in her features. Not a single doctor recognized a problem until the baby had a mal seizure. Another conflict actually occurred on the day Corbyn had a mal

seizure. Usually, Karyn's parents would come to babysit Corbyn while Karyn was in school by virtue of living nearby. That day, Karyn felt a sense of dread, as if something was going to happen to Corbyn. Karyn told her mother that she did not need to come over anymore. When her mother asked why, Karyn answered, because in case something happened, she needed to be with her daughter. Unsurprisingly, her mother scoffed and dismissed her concerns, saying such a thing would never happen. Reluctantly, Karyn went to school. However, suddenly, "there was this overwhelming sense of dread, literally. The most horrific feeling, ever, and I started to shake and was really scared." Upon feeling this rush of turbulence, Karyn immediately got into her car and drove home. As she approached the apartment, Karyn was literally shaking violently and was so afraid of what she was going to find. Here, although Karyn had a sense earlier in the day, she did not heed her own "gut," but instead followed her mother's suggestion and went to work, which I see as an evidence of Karyn's lack of trust in herself—in another word, self-confidence especially when compared with Karyn in the third and last section of her narrative. For now, it is important to understand Karyn's traumatic experience when facing Corbyn's disability.

### Facing Corbyn's Disability

The day Corbyn had a mal seizure, the day when Karyn rushed to home out of dreadful feeling and the day which Karyn faced Corbyn's disability, "was on January 19<sup>th</sup>, 1989." Karyn clearly remembers the date as if it were yesterday. It was the day that Karyn's drawn-out conflict with her mother and doctors was resolved because it was the day of Corbyn's mal seizure, which, without question, proved that Karyn's intuition was right all along. As Karyn had sensed, "something serious" indeed happened to Corbyn. Corbyn had suddenly experienced a brain bleed, and "with that bleed, came that grand mal seizure." The emotional impact of that series of

events that involved Karyn's experience of facing Corbyn's disability was to Karyn a traumatic experience.

When Karyn arrived home, with the most horrible feeling of dread, Corbyn was completely white, including her lips which normally were a bright red color and she was making no noise at all. Karyn learned that the seizure began exactly when she put her key in the door and it ended when she opened the door. After the seizure, Karyn explained, "because she lost all sphincter control with the seizure, Corbyn was having a bowel movement and was urinating and vomiting," all at once. Then, Karyn rushed to contact the doctor.

Doctors confirmed that Corbyn had a middle cerebral artery aneurysm, a giant artery aneurysm, and it needed to be clipped. Karyn's three-month-old daughter would have to undergo immediate emergency surgery. The surgery went well but in order to save her, the aneurysm was clipped right where the left middle cerebral artery bifurcates. Karyn explained this again in more simple terms:

"So essentially, to save her life, they took away all blood supply to the left lateral side of her brain...She was saved much to her chagrin, cause if you ask her, she'll tell you that she wishes that I had let her die, that she would prefer not to be alive because having to live this way is not the way she wants to be. She's too high functioning, so if she was lower functioning and didn't have the higher-level thinking skills and be able to compare herself to her brother and to other normal people. She would tell you she wishes I hadn't saved her. Of course, I tell her everyday I'm grateful for her existence and for how she has helped me to be in my life, because I am me because of her."

I pointed out the fact that she remembers the exact date. Karyn answered, "There's no way to forget that." Moreover, this event left Karyn with a "pretty severe PTSD around a date for

a long time.” Her PTSD, “panicking” in Karyn’s mind, subsided when Corbyn was seven years old. Until then, Karyn always had to be by Corbyn’s side on January 19; new year was never kind to Karyn. She would always be in a state of uncontrollable worry, fretting about the possibility that something bad would happen. Karyn reiterated, “It was a very traumatic day for me, even though Corbyn was saved. So, January 20<sup>th</sup> is her reborn day.” She pauses to think, “And then as the 19<sup>th</sup> would approach, I would become pretty panicky and unhappy,” but when Corbyn was about seven years old, Karyn’s anxiety abated. This repeated occurrence of memory that leads to re-live and re-experience an especially dreadful emotion is a symptom of PTSD.<sup>16</sup> The PTSD, which Karyn describes as, “a freak attack” lasted for seven years. Karyn recalled, “Took a long time for me to get over that, a long time.” And now she does not think about it at all but of course, it has been thirty-one years since Corbyn’s seizure. Going back to the traumatic day, after that day Karyn had only one objective: to cure Corbyn. Now, Karyn lived at odds with Corbyn’s illness and disability. As we will see in the next section of Karyn’s narrative, to some degree, from a psychological perspective, Karyn’s willingness and all the supports Karyn generated reveal the clear emergence of Karyn’s voice.

### Looking for Therapies, Yearning for a Cure

After the life-saving surgery, Karyn began to do everything within her power for her daughter – seeking therapists and taking Corbyn to receive various kinds of therapy. We will also see that Karyn’s sense of agency and her strong determination to fix her daughter’s disability are closely interconnected. At this stage, Karyn’s major conflict is with Corbyn’s disability and illness. Doctors, who were in tension with Karyn in the first section of Karyn’s narrative, now,

---

<sup>16</sup> “Post-Traumatic Stress Disorder,” National Institute of Mental Health, May 2022, <https://www.nimh.nih.gov/health/topics/post-traumatic-stress-disorder-ptsd>.

along with therapists, become partners to Karyn. A team consisting of Karyn, the medical staff, and therapists addressing disability, more specifically, Corbyn's disability emerged from these newfound partnerships. By this time, Karyn gained another teammate - she got married. In terms of support, the therapists stood by Karyn and aided her goal of helping Corbyn improve her use of movement. Furthermore, Karyn had a goal which she did not possess in the first section of her narrative. Karyn remarked, "She was perfect, she was everything that I needed, in order to make sure that I wouldn't drop out of school and that I would have a purpose, because *she* was the purpose. She became the entire reason for my life. So if there is a God, it's her[chuckle]. She is my purpose." This explains the dramatic transformation of Karyn's sense of agency and confidence after Karyn honestly faced her daughter's disability.

Corbyn began occupational therapy when she was 3 months old, as she could not use her right hand, arm, and leg, due to brain damage caused by the surgery. In the first year of undergoing several therapies, Corbyn learned to play with a ball with her right hand. Through play and plenty of encouragement, Corbyn made remarkable progress. Karyn wrote in her diary on July 30, 1988, "You can do almost everything now. You can switch the plate from mirror to bear, squeak the dog, move the cat."<sup>17</sup> More progress was noted on November 17 of the same year, "I finally saw you get yourself into the sitting position! Now you can stand, cruise, get back to the floor, crawl, sit, roll. You are such a big, proud girl."<sup>18</sup> Karyn deliberately omitted from her diary Corbyn's setbacks because she wanted to preserve every moment of pure joy above all else. Every moment of Corbyn's first achievements have been recorded with a sense of pride, love, and relief.<sup>19</sup>

---

<sup>17</sup> Lindsay Peterson, "A Mother's Love, A Daughter's Courage," reprint of a *Tampa Tribune* article, Woodland Manor Kennel, accessed December 14, 2022, [http://ahts.net/?page\\_id=79](http://ahts.net/?page_id=79).

<sup>18</sup> Peterson, "A Mother's Love."

<sup>19</sup> Peterson, "A Mother's Love."

Soon thereafter, Karyn realized Corbyn was not walking and was unable to speak. As a result, Corbyn began physical therapy at nine months, and then commenced speech therapy. In addition, Karyn and her husband realized Corbyn could not speak when they sent Corbyn to kindergarten. Karyn stated, “I didn’t realize there was anything wrong with her communication [chuckle]. My husband and I, we understood her just fine, but apparently, nobody else did.” Speech therapists helped her to start forming words and speak in coherent phrases and sentences. Karyn witnessed the marvelous progress therapists made with Corbyn. Her constant interactions with the therapists and her exposure to the various types of speech, physical, and occupational therapy, sparked something within her. Given her exposure to so many therapists, Karyn came to realize that the relationships she fostered with these therapists provided her with indispensable support and inspiration. Let’s hear this in Karyn’s words:

A doctor is a person that you go to, one time and they give you a diagnosis, they give you a referral, wherever. We did have a nurse practitioner, whom I truly loved, and she was very helpful, and she really, I believe, cared about me and my kid, but there is a different relationship that develops between a therapist and a child, or a therapist and the parents. Because you see them two times a week, every week, for a long, long time. And then you develop a relationship with them, and as you see the improvements in your child, you attribute those improvements to the guidance that the therapists have provided to you, because when...I really wanted Corbyn to be able to swing, seems like a silly thing, but I don’t know if you played on the swing, but Corbyn had a lot of sensory integration issues and she had a lot of motion sickness issues and a swing was not at all helpful to her. Some work with occupational therapy, could help with the car sickness . . . and also, with even brushing her hair, which might be painful to her. So [we used therapy] to desensitize her to these things and it was easy, as she improved, and of course, I attribute it to her therapist and the care that she was providing.

As we can see, in Karyn’s experience, occupational therapy helped Karyn to observe the clear effect on Corbyn; it allowed Corbyn to do things she couldn’t have done without receiving therapies. Furthermore, through working with therapists regularly, Karyn began to experience relational support from therapists that were not available from other medical staffs. Not long after, Karyn decided to become a therapist herself because she experienced the crucial support

therapists provide by closely attending to patients on an individual basis and reassuring their families. Equally as important, Karyn was excited at the prospect of becoming a personal speech therapist for Corbyn:

I thought I would be a doctor as well, but once my daughter had her aneurysm rupture and had to do all of her therapies—not that I didn’t think doctors were important, certainly they are. They helped to save her life. However, they are not the ones that you connect with, they are not the ones that you remember. The ones I remember are the therapists. I remember what the therapist did for her. I remember what the therapist did for me, and I decided I would go back to school and become a speech pathologist to help other kids originally with issues like my daughter. . . . I belonged there [VA Hospital], and it was truly where I was supposed to be.

Again, Karyn said assertively, “She gave me purpose.” Corbyn, or more specifically, Corbyn’s disability led Karyn to connect with therapists who, until then, she did not know existed. Despite this, meeting and getting to know them certainly helped Karyn realize her sense of purpose. Corbyn was not only a person whom Karyn had to take care of, but in a way, Corbyn took care of Karyn, spiritually and emotionally, by becoming “a guide” for Karyn’s life.

#### Karyn, a Therapist and a Mother

Karyn’s narrative arrived at a new turn once she became a certified therapist and Corbyn entered elementary school. Several relationship and emotional patterns represented in this last section still persist, for example, they experience the ramifications of some unresolved emotions between them, especially when looking at Corbyn’s words and actions toward Karyn. Many of the worries Karyn began to have in this section linger.

What is notable in this section of Karyn’s narrative is the remarkable growth of her own confidence and positivity toward her job. Her sizable personal growth, however, is accompanied by four kinds of tensions: (1) with Corbyn’s disability, a conflict that had lasted from the second section of Karyn’s narrative; (2) with Corbyn herself; (3) with Corbyn’s school system; and (4)

with Corbyn's friends (or lack thereof). Karyn's underlying objective, to some degree, causes these tensions and is one that continues from the second episode/section: "to best take care of oneself." For Karyn, this means teaching Corbyn to eventually become an advocate for herself. Karyn became a confident speech pathologist, and, in her narrative, we see a different person. Recall the day of Corbyn's first seizure. Even though Karyn knew she was right that something was wrong, she could not help but follow along with her mother's authority and went to school. Karyn complied despite having told her mother that she wanted to stay with Corbyn. In doing so, she not only capitulated to her mother's resolve, but also neglected her own agency by ignoring her motherly instincts. Back then, if someone told her she was wrong or dismissed her, she would relent or bite her tongue. However, today as a therapist, Karyn is assertive and confident in dealing with her clients. In this way, Karyn's sense of confidence developed over time, while she raised her child, Corbyn. It is easy to reason that bringing up Corbyn caused her to grow into her full potential. Karyn's perception of herself was as a very stubborn, hard-headed person. She has a consistent way of responding to any challenges she faces: "As far as I'm concerned, any challenge that came my way, I just went for it head-on...I'm really like a dog with a bone and I will not let it go until it comes to pass...I am obnoxious." Karyn described herself with a chuckle.

Of course, while raising Corbyn, who is now 33 years old, Karyn also aged and matured with the passage of time. However, we can say, at the very least, that there is a clear distinction in the way Karyn now perceives herself. Yet, all changes and developments are not without growing pains. After becoming a speech therapist and while working to "improve" Corbyn, another conflict arose, this time with Corbyn.



Although being a competent and a confident therapist allows Karyn to provide excellent guidance to her clients, it does not mean she always has a smooth relationship with Corbyn when she tries to be a therapist for her own daughter. Although, Corbyn's progress was remarkable as the *Tribune* once reported.<sup>20</sup> For some reason, the more Karyn tried hard to minimize the negative influences of having disability on Corbyn, the farther apart the relationship between herself and Corbyn seemed to grow. Karyn began to experience long-lasting, sometimes unspoken, conflicts with Corbyn, ironically, after Karyn had tried her best to alleviate the burdens of Corbyn's disability. In the midst of these tensions, Corbyn began to gravitate more toward her father. Like Karyn who said she has always been a "daddy's girl," "Corbyn also became "a daddy's girl." Karyn wears a disappointed, yet well-humored expression as she says, "Corbyn still doesn't want to go out with me. She likes her father [more]."

### Karyn's Sadness

With Corbyn and Corbyn's school system, Karyn can, at least, make a difference, but with Corbyn's friends, it was a different story. Karyn could not avoid nor always quell the frustration, sadness, and perhaps, loneliness that Corbyn experienced. Despite Karyn's best intentions and efforts toward helping Corbyn be as well-adjusted and to experience as much 'normal life' as possible, Karyn could not stop herself from experiencing a profound sense of disappointment when she saw Corbyn being ostracized and left out by the other kids at school.

Corbyn did not have much luck when it came to making friends. From kindergarten to third grade, Corbyn did have a few friends she made at school. However, when Corbyn was in

---

<sup>20</sup> Peterson, "A Mother's Love."

third grade, a new girl transferred into her class and impetuously asked Corbyn's friends, "Why are you friends with her?" Confused, they responded, "What do you mean?" The new girl explained: "Look at her, she's got a funny hand, and she walks funny, and why would you be friends with her?" And just like that, Corbyn's friends walked out of her life as if they were never there in the first place, despite all the memories they had made together. Unfortunately, this marked the beginning of Corbyn's periodic despondency.

When Corbyn was in eighth grade, her school held a dance for the student body. Corbyn was invited by a fellow classmate, but Karyn was wary of the girl's intentions. She believed that this invitation was something of a prank and that Corbyn would show up only to be stood up. After all, Corbyn had not been invited to any other notable social events at school, especially not by a random girl. Karyn decided to rent a limo to pick up the girl at her house to ensure that the girl could not back out: "Who wouldn't show up at the dance in a limo, right?" In the end, the girl lived up to her invite and Corbyn was able to go to the dance with her. Karyn, Karyn's husband, and their son kept the limo until the party ended. "We ran around town in the limo and got ice cream. It was funny," Karyn chuckled.

After that, there were a few attempts when Corbyn tried to kindle friendships, but all of them fizzled out for one reason or another. Every time Corbyn got a taste friendship, the relationship fell apart, leaving her to feel desolate. Karyn watched with a heavy heart as her daughter got her hopes up, only for them to be shot down by the fickle nature of childhood friendships. In Karyn's words:

You can see some of the darkness and the disappointment in her life in her blogs and her poetry. I was mostly disappointed *for* her. There was a time I was worried about suicide...I was more unhappy with her sadness when she was younger. I felt it was really sad that nobody would take the time to get to know her; that if they would give her a chance, she's really sarcastic and funny and smart, and she's different. Her brain is very different.

Driven by her concerns for her daughter's wellbeing, Karyn had Corbyn meet a clinical social worker in order to discuss her feelings, mental state, and views of the world. This social worker turned out to be the mentor with whom Corbyn had her last meaningful relationship. Their therapeutic relationship lasted for years until the social worker had to move to a different state. Although Corbyn was able to find another therapist later on, she soon decided to discontinue the service.

## Hope

Karyn's hope was directed to the response and attitude of her original family and society. First, she wished she had more financial and emotional support from her family. When I asked Karyn to name her hope in terms of Corbyn, she stayed silent for about two to three seconds before taking a deep breath as she prepared her answer. "In the beginning phase, when I had Corbyn, I was not able to get much support from my family," Karyn sighs. She found herself in a tight situation, but Karyn resolved to support her immediate family, no matter what. However, as time went on, she found that therapy and treatment fees were just more than she could afford. Karyn also wished she had more emotional support from her parents and siblings so that she could have had a wider social circle full of people who could see Corbyn for who she is. For example, hearing that Corbyn is a monster from her own sister was heart-breaking. And when the conflict broke out, her parents insisted that they could choose their own action. In other words, parents didn't support Karyn when she heard her sister and Karyn argued over Corbyn. Karyn would wonder if it would have been easier if she had financial and moral support from her family.

Second and ultimately, one of her greatest desires is for Corbyn to be understood and accepted in the world and by the society she lives in. For this reason, Karyn was delighted to see that there are many social media groups for people and families with the same diagnosis. A specific organization Karyn mentioned was CHASA the organization started out, also by a mother, Nancy Atwood whose daughter had had stroke. Karyn said she had talked with them quite a lot when there was only about five people. However, she witnessed the burgeoning of the organization. She said, “It’s much more powerful and much larger now because there are thousands of people on this Facebook group no.”

Social media groups may be popular now, but they were very rare 30 years ago when Corbyn was growing up. Karyn was able to see how people could easily form meaningful connections, provide genuine support, and exchange valuable information through those groups and she is relieved. For example, she said, “I think support from other people who had similar experiences and could maybe tell you that this is what you might expect. Although, in all honesty, I don’t know if it would have mattered, because the doctors told me what to expect and I told them they were wrong. So, I was determined to make her be who I wanted.” She referred to family’s lack of support.

## Resources

From Karyn’s story, two kinds of resources I found prominent. One is her husband, Rayn and her father who showed attitude to embrace and accept Corbyn’s disability as part of Corbyn. Ryan especially took the caring role. Karyn’s father, through her narrative, is described as a person who showed great sympathy toward Corbyn and Karyn who ceaselessly tried to improve the condition of Corbyn. On the other hand, Karyn’s job as an occupational therapist was a

enormous source to support her daughter and help her to adjust to life. The not profit organization of CHASA was also an important place that offered resources for Karyn. It was a place where Karyn participated in with Corbyn, arrange their children to become friends.

In this chapter, I described the relationship between mothers and their children's disabilities. Mothers react, fight, compromise and negotiate their expectations and hopes in regard to their children's disabilities with that of the actual disabilities of their children. These dynamics appear to show inconsistencies from the perspective of current literature of disability theology and psycho-social understanding of parents of children with disabilities as mothers' stories here do not follow or make sense. Current literature reveals a serious insufficiency in understanding and affirming mother's lived theologies as they are. Current disability theology focuses on providing normative theology of disability and does not realize there can be many different theology like mothers show. This becomes problem in the place of ministry or care practice, for most importantly, mothers are theologically in the place where their multiple disability theologies are considered as not theologically adequate. For this reason, current theology that is focused on finding/developing normative can function, to these mothers specifically as oppressive and less as spiritual resources. Furthermore, it cannot explain why mothers' hold on to seemingly contradictory theologies at one point and on different point in their lives. A similar limit is found when trying to explore mothers' thick descriptions from the dominant narrative provided in psycho-social literature.

From psycho-social perspective, unlike the order drawn by scholars in the field of psycho-social literature, the early sense or emotional state does not go away completely but remains. Mothers' psycho-spiritual reality is more complex and spiral than the linear dominant narrative. As such, the thick description of mothers in this chapter 4 reveals the insufficiency of

understanding of disability and parents' experience in current literature. If then, how could we understand the gap discovered in the literature and in mothers' lived experience? In the next chapter, I argue that the notions and framework that I propose are indispensable for understanding mothers' lived theology and its underlying meaning. Moreover, in this chapter, I lay the ground on which to draw an ethical norm that I will suggest in chapter 6. Then the strategic pragmatic task will follow in chapter 7. With this in mind, I will now turn to offer notions and a framework that can best assist to understanding mothers' lived theology.

## Chapter 5

### Mothers' Lived Theology: Interpretive Analysis

In the previous chapter, I explored the thick description of mothers' stories. By showing mothers' stories, I also delineated the complexity and subtlety of mothers' experiences that current literature cannot fully address. This chapter and the next chapter, chapter 5 and 6, are my attempt to overcome these limits. In this regard, Chapter 5 and Chapter 6 are broadly an interpretive task focusing to fill this gap by describing and interpreting why Alice and Karyn hold the theology they do. However, each chapter's focus is slightly different. While the goal of this chapter is to best understand Alice and Karyn's lived theology, chapter 6 is to elicit normative value from Alice and Karyn. Still, the activity of drawing out normative value encompasses interpretation, which is the reason why I broadly conceive chapter 6 also an interpretive task.

In Part 1, I offer description of the concepts that I propose in order to best make sense of Alice and Karyn's lived theology. These are "worldviews of disability," that I develop from Marno Retief and Rantsoa Letšosa's work on "models of disability,"<sup>1</sup> major components of worldviews of disability and the notion of "communities of worldviews" building on John Patton's communal-contextual paradigm. In part 2, I introduce the notion of "living webs of worldviews," appropriating Bonnie Miller McLemore's "living human web"<sup>2</sup> and Anton

---

<sup>1</sup> Retief and Letšosa, "Models of Disability."

<sup>2</sup> Miller-McLemore, *Christian Theology in Practice*, locs. 563–808 of 4272, Kindle.

Boisen's "living human document"<sup>3</sup> to capture mothers' lived theology. Finally, I apply these concepts to analyze mothers' lived theology more concretely. This framework is designed to evidence that mothers concurrently employ multiple worldviews regarding disabilities. Now, let me introduce these concepts and frameworks as a preparation to understand Alice and Karyn's lived theology.

## **Part 1. Concepts and Frameworks to Understand Mothers' Lived Theology**

### **"Models" to "Worldviews"**

In 2018, theologians Marno Retief and Rantoa Letšosa introduced various models of disability into the field of theology. Their article, "Models of disability: A Brief Overview," specifically aimed to assist pastors and theologians in the identification of multiple understandings of disability and promote their ability to construct such understandings.<sup>4</sup> Retief and Letšosa discerned various models of disability that shaped "people's perceptions and ideas about people with disabilities,"<sup>5</sup> and organized them into nine categories which I briefly introduced in Chapter 1:

The moral and/or religious model: Disability as an act of God,

The medical model: Disability as a disease,

The social model: Disability as a socially constructed phenomenon,

The identity model: Disability as an identity,

The human rights model: Disability as a human rights issue,

---

<sup>3</sup> Anton Boisen, *The Exploration of the Inner World* (Chicago: Willet, Clark, & Co., 1936), quoted in Charles V. Gerkin, *The Living Human Document: Re-Visioning Pastoral Counseling in a Hermeneutical Mode* (Nashville, TN: Abingdon Press, 1984).

<sup>4</sup> Retief and Letšosa, "Models of Disability."

<sup>5</sup> Retief and Letšosa, "Models of Disability," 1.



The cultural model: Disability as culture,

The charity model: Disability as victimhood,

The economic model: Disability as a challenge to productivity, and

The limits model: Disability as embodied experience.<sup>6</sup>

By identifying additional models informed by the narratives of mothers of children with disability, this study aims to build upon the foundations provided by Retief and Letšosa. I develop and expand these additional models to provide a set of frameworks that conceptualize the models' roles within mothers' lived theologies -- encompassing perspectives that include theo-ethical qualities, culture, narrative, language, and hope. For this reason, I expand Retief and Letšosa's framework of models and redefine them as 'worldviews' within this context.

According to Jon C. Tilburt, Medical Doctor of Division of General Internal Medicine at Mayo Clinic, the word 'worldview' is "derived from the German term *weltanschauung* (meaning 'view of the world')." <sup>7</sup> Tilburt adds that 'worldview' encompasses "a way of naming the life perspective from which one approaches problems, looks for solutions, and thinks about life options." <sup>8</sup> Given this definition presented, this paper defines 'worldview' as a philosophy of life that informs the perspective from which people examine their surroundings and address adversity.

With this definition in mind, when viewed as worldviews, the aforementioned models of disability imply and manifest something that surpasses a simple understanding of disability. Each perspective delivers explicit and implicit assumptions about what is important in life, including assumptions about human beings and their natures. In turn, every held worldview implies how a

---

<sup>6</sup> Retief and Letšosa, "Models of Disability," 1–8.

<sup>7</sup> Jon C. Tilburt, "The Role of Worldviews in Health Disparities Education," Supplement, *Journal of General Internal Medicine* 25, no. 2 (2010): S178–81, <https://pubmed.ncbi.nlm.nih.gov/20352515/>.

<sup>8</sup> Tilburt, "The Role of Worldviews."

person understands the wholeness of human beings and what life is. They implicitly and explicitly present concepts, skills, and values in one's interior life that they promote or discourage.

In reframing these models as worldviews, this study also seeks to expand on the theoretical foundations developed by Don S. Browning (1934~2010), a practical theologian at the University of Chicago Divinity School, and later utilized by Duane Bidwell. Browning suggests that modern psychological theories are best conceptualized as those that contain quasi-religious theories, given the dominant philosophical threads woven into modern psychology, in *Religious Thought and the Modern Psychologies: A Critical Conversation in the Theology of Culture* (1987).<sup>9</sup> In this sense, Browning argues that modern psychological theories are “meant to account for rather wide ranges of human experience— so wide, in fact, that they do not easily fit within the confines of rigorous experimental procedures or the narrow focus of behavioral or affective problems associated with the clinic.”<sup>10</sup> For example, Browning asserts among many factors, psychological theories’ aspects of religio-ethical thinking, conception of meaning and the way people ascribe meaning through interpretation make these psychological theories possibly as a worldview. While Browning concedes that these psychological theories do not intend to affect quasi-religious discourse and “begin in science,” they tend, “in time, to become a quasi-religious description of the world.”<sup>11</sup> That is, although not intended in the first place, these psychological theories function as description of particular worldview. This role of psychological theories draws parallel with Kathryn Tanner’s definition of theology that I mentioned in the

---

<sup>9</sup> Don S. Browning and Terry D. Cooper, *Religious Thought and the Modern Psychologies* (Minneapolis: Fortress Press, 2004), 3–4.

<sup>10</sup> Browning and Cooper, *Religious Thought*, 3–4.

<sup>11</sup> Bidwell, “Hope and Possibility,” 4.

introduction, an interpretive lens.<sup>12</sup> As such, I want to create this kind of connection in my own study between models of disability and worldview.

Browning's assertion of the deep connection between theology and modern psychologies relies heavily on his definition of religion as "a narrative or metaphorical representation of the ultimate context of reality and its associated world view, rituals, and ethics."<sup>13</sup> Such a definition seems almost intentionally broad, with the door being left open for other perspectives—especially those that are not 'religious' in a more conventional definition of the word—to be seen as "religious" or, at the very least, "quasi-religious." In essence, anything that makes efforts to engage with Browning's helpfully vague "ultimate context of reality" can be conceptualized as such. I interpret this nebulous "ultimate context of reality" to mean certain values or ideas that function to ground a person's existential being and elicit a related ethical response.

Consequently, if manipulated rigorously enough, almost anyone's perspective, regardless of its objective viability, can be interpreted as quasi-religious insofar as it encapsulates elements of that person's psychological, spiritual, and ethical systems, or acts—in Mircea Eliade (1907~1986)'s words, who was a Romanian historian of religion and a professor at Chicago Divinity School, the "sacred center that guides people's lives."<sup>14</sup> This is congruent with the way John J. Thatamanil, associate professor of theology and world religions at Union Theological Seminary in New York understood religion as a "comprehensive qualitative orientation that functions as both an interpretive lens and a therapeutic regimen would support this stance."<sup>15</sup> These scholars' understandings of religion reflect the recent trend of pluralistic reality through

---

<sup>12</sup> Tanner, "The Difference Theological Anthropology Makes," 567–79.

<sup>13</sup> Don S. Browning, "Can Psychology Escape Religion? Should It?" *International Journal for the Psychology of Religion* 7, no.1 (1997), quoted in Terry D. Cooper, *Don Browning and Psychology: Interpreting the Horizons of Our Lives* (Macon, GA: Mercer University Press, 2011), 3.

<sup>14</sup> Cooper, *Don Browning and Psychology*, 38.

<sup>15</sup> John J. Thatamanil, *Circling the Elephant: A Comparative Theology of Religious Diversity*, *Comparative Theology: Thinking across Traditions*, vol. 8 (New York: Fordham University Press, 2010).

which people seek religious or spiritual wisdom not restricted by instructional religion. Moreover, this phenomenon features scholars' increased openness toward what considered as "religion." Rather than focusing whether certain religion is institutionally considered religion, ideas or thoughts that are not explicitly religious but operate religiously are becoming to receive more attention. For instance, even when some prioritize their nation or money—contributing to nationalistic or capitalistic outlooks, respectively—over anything more obviously religious, these priorities (and the social sciences that inform them) shape and provide structure to their interior lives in a way that Browning would argue becomes quasi-religious.<sup>16</sup>

Before going further, we must also address what motivates Browning to interpret psychological theories from a quasi-religious perspective. Arguably, this comparative framework facilitates and adds clarity to an evaluation of the extent to which any specific perspective has functional value for individuals. These perspectives, by nature, are often "quasi-religious" given that they were not conceived to become religious discourse and consequently may not fully function as "right" and "good" religion—which can broadly be defined as maximizing humanity.<sup>17</sup> Consequently, secular—or 'quasi-religious'—worldviews must be discerned from those put forward by more 'authentically' religious scholars. A prime example of this specific act of sifting the quasi-religious from the authentically so can be found in Duane Bidwell's work, "Hope and Possibility: The Theology of Culture Inherent to Solution-Focused Brief Therapy," which seeks to analyze the worldview of solution-focused brief therapy and provide a subsequent evaluation from the Christian theological perspective.<sup>18</sup> This kind of work is crucial to the field of pastoral theology, in which religious caregivers attempt to use psychological resources to meet

---

<sup>16</sup> Browning and Cooper, *Religious Thought*, 2.

<sup>17</sup> This is what I understand as one of the primary functions of religion.

<sup>18</sup> Bidwell, "Hope and Possibility, 3–21.

a theological goal. Within this chapter, I also intend to build upon Bidwell's work, by using Browning's tools for analyzing quasi-religion, to explore the many differing perspectives on disability. Browning's framework is excellent at elucidating the composite values that contribute to certain worldviews, better enabling "a critical conversation between Christian thought"<sup>19</sup> and the social sciences. This, in turn, brings us closer to answering how viable certain schools of thought become when viewed from a Christian perspective. The development and use of this framework alone supports the notion of pastoral theology's tendency to actively engage with the social sciences, especially psychological resources.

In Browning's work, this framework functions as sort of a "gatekeeper" to discern whether certain social sciences are compatible with Christian beliefs and their employment. I use this framework with both similar and dissimilar aims: while I do intend to explore and identify values and their hierarchy within various worldviews, I do not ask whether such worldviews on disability are theological nor determine to what degree they are theologically sound. Rather, my central goal is to re-evaluate these various worldviews on disability out of the belief that understanding disability is not merely coming to an understanding of disability, but encompasses much broader, and often polyvalent, quasi-religious notions. While doing so, I explore not only what theological ideas are imbedded in certain worldviews, but also how these ideas function socially, psychologically, and spiritually in the worldviews of mothers. Their realities are often a composite mixture of different worldviews, which I characterize as *a mother's living web of worldviews* drawing upon Bonnie Miller-McLemore's concept of the Living Human Web.<sup>20</sup>

---

<sup>19</sup> Browning and Cooper, *Religious Thought*, 15.

<sup>20</sup> Miller-McLemore, *Christian Theology in Practice*, locs. 563–808 of 4272, Kindle.

## Components of Worldviews

Before progressing to such discussions, however, we must first answer the foundational question of what determines whether a worldview qualifies as quasi-religious thoughts.<sup>21</sup> A worldview must be understood as being made up of various elements, including concepts such as ultimacy, various notions of personhood, and what constitutes a good life, while also being influenced by ethics, practices, and communities. A worldview is also generally represented by narratives or metaphors that include concepts of ultimacy.<sup>22</sup> In this section, I will explore each component.

First, let's look at what ultimacy means. While Browning views metaphors of ultimacy as underlying assumptions about the world, Bidwell defines this ultimacy as “a certain understanding of the world and an ethics of obligation that arbitrate what human needs and tendencies are considered legitimate and suggest how human beings are obligated to act toward one another.”<sup>23</sup> Bidwell's broader description of ultimacy is helpful and worth examining in full:

Metaphors of ultimacy answer the questions, “What kind of world do we live in?” and ‘What is its most ultimate context?’ Further, metaphors of ultimacy are the images and ideas we use to describe life as we experience it. These metaphors are not a direct representation of reality but attempts to explain life in terms that are easier to understand from our limited perspective. For example, Freud used metaphors of psychology (sex, drive, life) to describe the ultimate nature of the world.<sup>24</sup>

The metaphors of ultimacy describes core concepts of worldviews; what becomes a major notion to understand human action, motivation and possibly sources that support human beings to live their daily lives. Most likely, the metaphors of ultimacy becomes a fundamental notion that ground most of the components that follows such as hope, understanding of ideal human beings, a good life, ethics, practices, and communities.

---

<sup>21</sup> From this point on, I will use *worldview* and *quasi-religious thoughts* interchangeably.

<sup>22</sup> Browning and Cooper, *Religious Thought and the Modern Psychologies*, 248.

<sup>23</sup> Bidwell, “Hope and Possibility,” 4.

<sup>24</sup> Bidwell, “Hope and Possibility,” 9–10.

Second, Andrew Lester, Professor Emeritus of Pastoral Theology and Pastoral Counseling at Brite Divinity School, provides understanding of two kinds of hope, the dynamics of these two kinds of hope, and future stories that will be important analytical tool when we explore and discern each worldview's influence to mothers especially to discern their psycho-spiritual state. Each worldview contains its own vision of hope, which can be made somewhat more concrete through Lester's suggestion that there are two different kinds of hope: finite hope and transfinite hope.<sup>25</sup> Finite hope entails a desire a person has toward finite, often concrete objects such as "our hope for a pay raise, acceptance into a certain school, a good grade, a positive word from an inquiry."<sup>26</sup> On the other hand, as the term 'transfinite' itself suggests, transfinite hope refers to hopes that transcend the concrete objects of finite hopes; it is a hope without tangible ideas or objects, but rather based in the act of believing in the underlying providence of God.<sup>27</sup> Thus, no matter a person's circumstances, they can continue to uphold the faith that God or the Divine's good will remains constant and receive life-giving resources. This categorization of hope, then, suggests that not all hopes are life-giving unless the hope have quality of transfinite hope. When finite hope is broken, it can easily lead a person to despair as it relies on something that is, by definition, fleeting and transient.<sup>28</sup> Inversely, in being rooted in a person's trust in God or the unfailing Divine rather than finite objects, a person's transfinite hope remains intact even when the finite hope is lost. In this way, Lester argues that transfinite hope is the prerequisite for all finite hope. He also discusses the notion of hope specifically in a Christian context; however, I think the object of God or the Divine for transfinite hope can go beyond of the idea of Christian God. They can be replaced by other objects or can be found in life

---

<sup>25</sup> Lester, *Hope in Pastoral Care and Counseling*, 59–71.

<sup>26</sup> Lester, *Hope in Pastoral Care and Counseling*, 63.

<sup>27</sup> Lester, *Hope in Pastoral Care and Counseling*, 67–69.

<sup>28</sup> Lester, *Hope in Pastoral Care and Counseling*, 74–83.

philosophies or attitudes harbored by those who have different religious beliefs or none at all. For instance, most of the worldviews on disability that I present later in this dissertation are actually non-Christian or non-religious from the outset, but nevertheless retain an element of hope.

Lester also discusses types of future stories that lead a person from hope to despair, a term that he defines as “disturbances of the ‘hoping process’ in which our capacity to hope is lost, blocked, distorted, or in some manner impaired.”<sup>29</sup> Furthermore, the hoping process is, at its core, the process of imagining possibilities, and consequently does not negate the suffering or pain of the present in thinking about the future. Hope that is life-giving, then, offers a person a vision of an open future rich with possibilities, while also embracing the present moment. There are, inversely, future stories that are not rooted, but seek to escape from a more grounded position. Although these narratives ostensibly seem like stories of hope, they are in fact dysfunctional, often preventing someone from perceiving their objective reality. From Lester’s perspective, hope, as it manifests in worldviews, can have both finite and transfinite facets, which is a notion that I will carry forward when exploring the nature of hope in several worldviews. That said, despite utilizing Lester’s postulations, I do depart from his primary argument by instead proposing that some forms of finite hope may have a positive, life-giving effect on mothers. This reasoning will be further discussed with regards to the medical worldview in Part 2.

Third, an understanding of the human being is usually included in a worldview and encompasses some notion of human nature as well as what fosters or creates human fulfillment. This is called the human predicament. Understanding of the human predicament includes

---

<sup>29</sup> Lester, *Hope in Pastoral Care and Counseling*, 72.



anticipation of a vision of hope and the sense of direction that comes with it; it asks where to go and how to get there. In suggesting methods of attaining human fulfillment, discourse often roots itself in ethics derived from the way that that specific worldview understands human beings.

Fourth, based on their worldviews' implicit conceptualization(s) of the world, hope, and the human condition, a person establishes a vision of what constitutes 'the good life.' As Browning delineates, all worldviews encompass variations on "the good life, and encourage a particular form of trust, devotion, and faith in human possibilities. They attempt to describe 'the way things are' even beyond sense experience."<sup>30</sup> The discussion of good life is also referred to as ethics.<sup>31</sup> As such, a person's ethics will shape their vision of a good life and provide a path by which to achieve it.<sup>32</sup> Accordingly, the specifics of what constitutes a good life remains a core question in the field of ethics and is undoubtedly impacted by the points of view of any given individual. While they do not explicitly promote specific practices, in assigning either more or less value, motivation, or desire toward certain ideas and practices, each worldview puts forth its own implicit model of what it means to live a life worth living. Thereby, when people engage in practices connected to a particular worldview, they signal their involvement in that respective worldview. Browning articulates a similar concept in his discussion of 'rituals.'<sup>33</sup> Here, the term 'ritual' is taken in its broadest sense to refer to the repetition of a meaningful practice that, when undertaken, strengthens the core philosophy of a particular discourse.

Fifth, one's idea of self-identity is intricately related with which kind of worldview a person ascribes to. When engaging in any sort of discourse, an individual is likely disclosing

---

<sup>30</sup> Cooper, *Don Browning and Psychology*, 34.

<sup>31</sup> Robin W. Lovin, *An Introduction to Christian Ethics: Goals, Duties, and Virtues* (Nashville, TN: Abingdon Press, 2011), vi–vii.

<sup>32</sup> Browning and Cooper, *Religious Thought*, 34–35.

<sup>33</sup> Browning and Cooper, *Religious Thought*, 248.

their sense of identity and is left vulnerable for others to judge this person for the worldviews their signaled identity implies. Alternatively, they may instead seek to intuit their positioning relative to their conception of an ideal human condition—which has, of course, been shaped by their worldview. In instances in which this positioning feels less desirable, an individual will likely seek to move toward a more ideal human condition, acting on the values implicit within their worldview(s). In this sense, a person will always seek to locate themselves within their worldview.

Interestingly, within this framework, the degree to which an individual despairs or hopes can imply the extent to which they hold and act according to a certain worldview. For example, if we see what discourse a person adheres to, it is possible to infer (at least roughly) how that person understands or identifies themselves or, to push further, which worldviews they value. The correlation between discourse and worldviews has been demonstrated in “The Stories of Parents of Children with Mental Disabilities: ‘Triumphal’ vs. ‘Absurd’ Narratives”<sup>34</sup>: the more parents feel that disability is abnormal, the more they are inclined to embrace miracle narratives that resolve with a complete removal—or ‘curing’—of their child’s disability.<sup>35</sup> In contrast, parents, who instead acknowledge that their child’s disability is a socially constructed concept and not an essential difference in their child’s nature do not necessarily resonate with miracle-filled triumphal stories.<sup>36</sup> While all of these parents are able to accept their children’s disabilities, those who cleave to triumphal stories lack the psychological capacities to accept disability, especially when associated with their own children when compare to those parents who understand the

---

<sup>34</sup> Jeongyun Hur, “The Stories of Parents,” 47–62.

<sup>35</sup> Hur, “The Stories of Parents,” 47–62.

<sup>36</sup> Hur, “The Stories of Parents,” 47–62.

constructiveness of the term “disability.” Therefore, and often inadvertently, they seek to eliminate it.<sup>37</sup>

Accordingly, one’s worldviews and the related discourse on human nature and fulfillment influence their own conceptions of themselves and the goals they view as desirable.

Fundamentally, worldviews impact thought, and people seek to alter themselves to better adhere to the construct of the ideal human condition in their mind’s eye. Similar ideas on people’s worldviews and their perception of them can be found in Stephan Madigan’s interpretation of Michael Foucault’s idea. In observing various perspectives as quasi-religious, according to Madigan, Foucault also presents a perspective that an individual’s identity is constructed intricately in relation to its context.<sup>38</sup> That is, an identity is usually a result of the reconciliation between one’s current place in a given context and “the selves we normally remember.”<sup>39</sup> Both, according to Foucault, “are influenced by and reproductive of cultural and institutional norms.”<sup>40</sup> For this reason, in line with Foucault’s viewpoint that culture and discourse is inherently political, to him, identity and the way people conceive of it is also “profoundly political both in [its] origins and in [its] implications”<sup>41</sup>

Lastly, specific communities seek to uphold and engage with each discourse of worldviews because full-blown religions are contingent upon “an identifiable community” them.<sup>42</sup> Consequently, these communities exercise power; as a result, certain dynamics of power are inevitably instilled. These religious communities are, in many cases, hence inclined to perpetuate these power dynamics as part of the maintenance of the status quo. To return to

---

<sup>37</sup> Hur, “The Stories of Parents,” 47–62.

<sup>38</sup> Madigan, *Narrative Therapy*, 36.

<sup>39</sup> Madigan, *Narrative Therapy*, 36.

<sup>40</sup> Madigan, *Narrative Therapy*, 36.

<sup>41</sup> Madigan, *Narrative Therapy*, 36.

<sup>42</sup> Browning and Cooper, *Religious Thought*, 248.

Madigan's understanding of Foucault, participants are both of and subject to certain kinds of power use of knowledge to judge, condemn, classify, and influence "a certain mode of living."<sup>43</sup> Consequently, "the relational and constitutive dimension of power/knowledge"<sup>44</sup> is embedded in culture and social and psychological realities, especially in specific discursive cultural practices and related cultural discourse.<sup>45</sup> This, in turn, implies the existence of a group or individual within these religious communities that holds the most power and likely has various methods of executing such power.

Thus far, we have seen that the models of disability proposed by Retief and Letšosa can be understood as worldviews, and that these worldviews entail an element of a quasi-religious quality, as evidenced through theories put forth by Browning. These worldviews can be easily found in people's thoughts as people subscribe to and participate in some or all of the nine aforementioned worldviews. Whether such belief and participation are based on reason or circumstance remains unclear and such a notion presents an interesting research topic for further research such as what determines which worldviews a person will adopt. For me, when observing people holding on various worldviews, it appears to be possessing a quality of "faith" as Browning points out: "religion is at bottom a 'faith in a way things are' that goes beyond sense impression and narrowly empirical description."<sup>46</sup> As, "these metaphysical principles *elicit attitudes of trust, faith, hope*" (emphasis in original).<sup>47</sup> Like people draw trust, faith, hope to certain metaphysical principles, I argue that people can be in similar relationship with different

---

<sup>43</sup> Madigan, *Narrative Therapy*, 29.

<sup>44</sup> Madigan, *Narrative Therapy*, 29.

<sup>45</sup> Madigan, *Narrative Therapy*, 29.

<sup>46</sup> Browning, *Religious Thought*, 248.

<sup>47</sup> Cooper, *Don Browning and Psychology*, 35.

worldviews of disability. Worldviews become sources for people to trust, to put faith and to hope with different worldviews as we will see in Alice and Karyn.

Worldviews lack the uniformity and stability to be easily or cleanly divided, as people naturally shift with their social environments and accumulate experience over time. Some worldviews can be at odds with one another, perhaps none more clearly than the medical worldview and the social worldview – the latter of which was born out of resistance to the medical worldview’s conceptualization of human flourishing. Others, however, like the social worldview and the human rights worldview, are more like two Venn diagrams with an overlap, sharing some, but not all, aspects. Yet, in other cases, certain worldviews have impacted the propagation of further worldviews. Take the social worldview of disability, for example: it strongly influenced the emergence of the legal and the human rights worldviews of disability, which were initially conceived as a single worldview, only to later separate into two distinct worldviews—each pursuing different ideals. With this understanding of worldviews, now, I propose that these types of worldviews are shared by people and private- or public-sector agencies, within what can be called a “community of a worldview.” John Patton’s communal-contextual paradigm helps us to understand this.

### Community of Worldviews

Having previously established that models of disabilities can be understood as worldviews, I will now build upon communal-contextual paradigm of John Patton, Professor Emeritus at Columbia Theological Seminary, to evidence that a sense of community can be constructed by sharing worldviews. In other words, I argue that it is possible to perceive people sharing common worldviews as an expression of a community that encompasses an interpretive

lens, a culture, and specific practices, even when it lacks the appearance of or formal recognition as a community. Then, this conceptual understanding can make possible to understand multiple communities of worldviews mothers simultaneously hold on to.<sup>48</sup>

Before Patton, theologians such as Don Browning and Elaine Graham considered the practice of community to be the locus of pastoral theology since the late 20<sup>th</sup> century. Browning, for example, appropriates Aristotle's notion of 'phronesis' or 'practical moral reasoning' in relation to communities and asserts that community itself has its own skill and wisdom enacted within communal practice.<sup>49</sup> Graham, much like Browning, also sees the subject of pastoral theology as the "pastoral practice of the faith-community itself."<sup>50</sup> It is worth noting, here, that the faith community's theology is widely perceived as entrenched in the core values upon which human culture was based at earlier moments in the field of pastoral theology. While the idea of community referred to by both Browning and Graham is undoubtedly this rather limited 'faith-community,' Patton's discussion of community is somewhat broader and therefore applicable to non-faith-communities as well. In applying it to all of these communities, we can develop a deeper understanding of mothers' lived theology which I later identify as a "living webs of worldviews."

First, though, let us examine John Patton's communal-contextual paradigm in greater detail in order to better comprehend how sharing worldviews can conceive as activity of community. The communal-contextual paradigm of pastoral theology was developed in 1993 by John Patton through his book, *Pastoral Care in Context: An Introduction to Pastoral Care*.<sup>51</sup>

---

<sup>48</sup> Perhaps one reason why different communities of worldviews can coexist is their lack of physical presence or official membership.

<sup>49</sup> Browning, *Fundamental Practical Theology*.

<sup>50</sup> Graham, *Transforming Practice*, 7.

<sup>51</sup> John Patton, *Pastoral Care in Context: An Introduction to Pastoral Care* (Louisville, KY: Westminster John Knox Press, 1993).

Before Patton's communal-contextual paradigm was developed, pastoral care was mostly understood as and followed the classical (clergy-centered) and clinical (psychological) paradigms.

In the classical paradigm, Clebsch and Jaekle proposed care to be healing, sustaining, guiding, and reconciling,<sup>52</sup> all of which were traditionally understood to be primarily provided by people with religious authority, such as ministers, priests or pastors. Patton referred to this as 'the classical paradigm.'<sup>53</sup> As the field of spiritual care and counseling began to interact with the field of psychology, those who were in caregiving positions found that the quality of care notably improved. Thus the interaction between theology and psychology becomes popular. Patton termed this new model of care 'the clinical paradigm.'<sup>54</sup> The development of feminist and liberation theological approaches influenced the continued development of pastoral care, raising awareness of the larger context of the person providing care. Within this context, Patton—who was, himself, a minister, care giver, and theologian—came to realize that, although these paradigms strengthened the Christian-oriented tradition and catalytic expansion of the field of pastoral care by seeking and establishing interdisciplinary studies, they did not pay sufficient attention to the human person's context.<sup>55</sup> Within this framework, the term 'context' is wielded broadly to encompass the dynamic social, political, and economic circumstances and communities that surround a care seeker.<sup>56</sup> To use Bonnie Miller-McLemore's term, these circumstances collectively form "the living human web."<sup>57</sup>

---

<sup>52</sup> The function of communities is to be nurturing, "empowering," and "liberating." William A. Clebsch and Charles R. Jaekle, *Pastoral Care in Historical Perspective* (Lanham, MD: Jason Aronson, 1994), quoted in Carroll A. Watkins Ali, *Survival and Liberation: Pastoral Theology in African American Context* (Saint Louis: Chalice Press, 1999).

<sup>53</sup> Patton, *Pastoral Care in Context*, 4.

<sup>54</sup> Patton, *Pastoral Care in Context*, 39.

<sup>55</sup> Patton, *Pastoral Care in Context*, 40.

<sup>56</sup> Patton, *Pastoral Care in Context*, 40.

<sup>57</sup> Miller-McLemore, *Christian Theology in Practice*, locs. 563–808 of 4272, Kindle.

Patton's proposed communal-contextual paradigm accounts for this human web of contexts through its two aspects: the Communal and the Contextual. Context, which to Patton is synonymous with culture, influences a person's oppression and healing: gender, race, power, and cultural myths impact a person's way of thinking.<sup>58</sup> Accordingly, the communal dimension specifically refers to a community's capability of giving care, quite literally serving as a caregiver.<sup>59</sup> Consequently, in Patton's words, "the power of pastoral care [rests] in the fact that it is the care given by the community, not by the individual pastoral caregiver alone."<sup>60</sup> By arguing that communities themselves can provide care, Patton, to some degree, democratizes and decentralizes the power that had previously been solely granted to ministers. He argues that both a layperson and a minister alike have the ability provide care. As such, from the communal-contextual context, pastoral care significantly shifts to be a "ministry of the Christian community," rather than that of any sole individual.<sup>61</sup> Through this logic, Patton thus expands the subject of care from that of a person with clinical or religious authority, to that of a community.

This, then, raises the question of what Patton envisioned by the word 'community.' In *Pastoral Care in Context*, Patton defines community as a group of people who feel a 'sense of belonging,' be remembered, be acknowledged, and to feel that there is something important that they are a part of.<sup>62</sup> To that end, he references William Willimon's five characteristics that constitute community: "common identity, common authority, common memory, common vision,

---

<sup>58</sup> Patton, *Pastoral Care in Context*, 42.

<sup>59</sup> Patton, *Pastoral Care in Context*, 27.

<sup>60</sup> Patton, *Pastoral Care in Context*, 35.

<sup>61</sup> One of the most important kinds of care provided by a community, according to Patton, is the act of "remembering." More specifically, in Patton's words, pastoral care "takes place through remembering God's action for us, remembering we are as God's own people, and hearing and remembering those to whom we minister." Patton, *Pastoral Care in Context*, 15.

<sup>62</sup> Patton, *Pastoral Care in Context*, 20–21.



common shared life together, and common shared life in the world.”<sup>63</sup> He adds that, while not all communities will exhibit all five of these characteristics, they will have at least some.<sup>64</sup> Although Patton, of course, constructs these ideas while specifically considering religious communities, he grants space for secular communities, such as those found in hospitals and schools.<sup>65</sup> Both locations/communities/kinds of institutions also function as caring communities given their nature as caring spaces designed to either nurture (schools) or heal (hospitals)—both of which are agendas essential to pastoral care.

Within this paper, I seek to push this notion of community yet further. That is, communities are not bound by physical presence or designated title, but (can) exist whenever people share a common worldview. I also propose that when any worldview is shared by a group of people, it can generate a community. I term this phenomenon a ‘worldview community.’ This notion of community meets four of Willimon’s five characteristics of a community: common identity, common authority, common memory, and common vision. Sharing stories also contributes to building communities.<sup>66</sup>

This is indicated in the cases of Alice and Karyn, which demonstrate that participation in a medical worldview community is not limited to one physically-bounded space like a hospital or even one medical field. Instead, non-profit organizations, people who provide Social Security services, public agencies, and family members can all hold a medical worldview. Moreover, the adoption or harboring of this worldview does not limit any participant from holding or exercising any other kind of worldview, regardless of its nature. Most notably, Alice and Karyn themselves

---

<sup>63</sup> Patton, *Pastoral Care in Context*, 21.

<sup>64</sup> Patton, *Pastoral Care in Context*, 21.

<sup>65</sup> Patton, *Pastoral Care in Context*, 21.

<sup>66</sup> Gene Combs and Jill Freedman, “Narrative, Poststructuralism, and Social Justice: Current Practices in Narrative Therapy,” *The Counseling Psychologist* 40, no. 7 (2012): 1034.

strongly adhered to this worldview at various points in their lives and continue to uphold it now—albeit in a perhaps lesser degree—when interpreting and understanding their children and their children’s disabilities.

In this section, I mostly engaged in developing conceptual frameworks such as “worldviews of disability,” what constitute the notion of worldviews, and “community worldviews.” These concepts will play as analytic tools to conceptualize mothers’ lived theology in the next section. From now on, I will begin to apply these concepts to mothers’ stories to delineate different worldviews of community playing out and construct “living web of worldviews.” Before we delve into explore Alice and Karyn’s living web of worldviews, Now, I will introduce what I mean by “living web of worldviews.”

## **Part 2. Interpretation: Living Web of Worldviews as Mothers’ Lived Theology**

In Chapter 3 - Method, as part of practical/pastoral theological work, I describe two goals. First is to provide or proclaim affirmation of a certain phenomenon as theologically meaningful. Second is to “provide positive improvement of the quality of lives or the condition of the status quo in regard to theological issues.”<sup>67</sup> I added that the role of a practical theologian is to strike the balance between these two tasks. While I attempt to conduct the second work answering how improvement can take place and why it is needed in upcoming chapters 6 and 7, the goal of this chapter is to describe and affirm a phenomenon that is theologically meaningful. I suggest “living web of worldviews” as a phenomenon of living human document needs to be fully affirmed as the lived theology of mothers of children with disabilities.

---

<sup>67</sup> Jeongyun April Hur, “Finding the Practical Wisdom of Mothers of Children with Disabilities: Narratives in the Construction of Mothers’ Lived Theology” (Dissertation, Claremont School of Theology, 2022), 90.

The “living web of worldviews” is the notion that I appropriated, originally by Anton Boisen as “living human document”<sup>68</sup> and modified by Bonnie McLemore to be “the living human web”<sup>69</sup> to demonstrate the different worldviews presented in Alice’s and Karyn’s respective narratives. Interestingly, both of these terms are developed to identify the subject matter of pastoral theology and in this way, these terms describe the history of development of pastoral theology. What is more interesting is that this clarification of subject matter took place first in the field, and both of these theologians capture and describe what is happening in the field rather than intended to marshal the movement. When I coin this term, I am also doing it not to prescribe but describing what I observed from mothers’ lived theology. In this vein, I argue that the various worldviews on disability are also an adequate subject matter of the field of pastoral theology. Then, what makes various worldviews of disability, particularly in relation to mothers, a subject matter of pastoral/practical theology? Examining different worldviews advances our understanding of mothers’ psycho-social state and their lived theology in two ways. First, each worldview functions to foster sense of community that allows mothers to sustain. I will explore more deeply the pastoral function of each worldview in the next chapter. Second, although worldviews are not theological from the outset, in the previous chapter I showed that each worldview can be viewed as quasi-religious idea. This way of interpretation allows us to interpret people’s value, belief, although the subject/ object differ, different worldview consist of people’s lived theology.

The notion of mothers’ living web of worldviews follows the tradition of pastoral theology, especially the aspects of “web,” “living” and “contextual.” These mothers live within

---

<sup>68</sup> Anton Boisen, *The Exploration of the Inner World* (Chicago: Willet, Clark, 1936), quoted in Gerkin, *The Living Human Document*.

<sup>69</sup> Miller-McLemore, *Christian Theology in Practice*, locs. 563–808 of 4272, Kindle.

an abundance of diverse worldviews. The expression “web” astutely captures the complex reality of the ever-changing, dynamic relationships mothers have with various perspectives of disability. That is, multiple perspectives on disability simultaneously operate in a mother’s lived theology, playing together like an orchestra to serve various needs of mothers’ psycho-spiritual, communal and pragmatic and support and sustain mothers’ daily lives. The living web of worldviews becomes psycho-spiritual resources for mothers.<sup>70</sup> One worldview can be an oboe, for example, and another can be a violin—they look different and make completely different sounds. Yet their interplay creates something greater than the individual parts—something beautiful, pleasing, useful—that could not be created with only one of the instruments. Such is the case for the medical, identity-based, and restriction-related understandings of disability that are found in Alice’s narrative. In the same vein, the medical worldview, the identity worldview, and the moral and/or religious worldview can be observed in Karyn’s narrative.

In mothers’ place of living, each worldview presents different resources and functions to mothers. While doing so, their narratives contain idiosyncratic weaving, twisting, warping, and distortions created by the dynamic nature of their worldviews interacting with one another and with the world around them. One perspective, among many, may bear sizable weight for a particular individual, but not for another. That is, each view’s ‘worth’ is entirely personal and subjective; multiple views can be balanced (or otherwise) by sharing equal influence or one view can outweigh others at a specific time or in a certain condition. Under the notion that these webs are ever-changing and mold themselves to align with a wielder’s specific needs and philosophies, I argue that the following conditions are individualized and significant: how mothers are influenced by each perspective; the degree to which mothers adhere to a particular worldview;

---

<sup>70</sup> The notion of the living web of worldviews functioning as psycho-spiritual resources will be explored in detail in the next chapter when I look in depth at mothers’ practical wisdom.

the timing as to when they choose to exercise ideas associated with one or more standpoints; and what kinds of and which perspectives are active within particular conditions.

Mothers' living web of worldviews, contain, as the term itself indicates, its own living dynamics. It is a living conception that exists in constant motion, responding to, and lending itself to the situation in which a mother exists and lives. A pliable set of ideologies enables and supports mothers' webs of relationships with diverse worldviews and sustains mothers' ecosystems of relationships that contain various perspectives on disability. In this regard, a mother's theology of disability cannot be considered as static or fixed.

This illustrates that a mother's living web is highly contextual. It is the result or process of applicable reconciliation of the realities mothers experience and the meanings of disability. A mother's disability theology is intricately related to the context in which they are situated—where they put their feet, who they encounter, and in their everyday activities and interpersonal interactions: their material reality. Each different orchestra mothers form with their instruments of different understandings of disability is part of a complex process of negotiation and acceptance of their children's distinct embodiment(s) that must be fully acknowledged and affirmed in theological studies, psycho-social literature, and in the places where caring occurs. I also propose that it is because this reality—namely, the 'living web of worldviews'—was not addressed sufficiently 1) current disability theology's assumption that there are more theologically right understandings of disability and 2) dominant psycho-social understanding of parents of children with disability both fall short in understanding mothers' lived theology and their realities.

Browning's lens of quasi-religious discourse in viewing various worldviews and the pastoral functions that each worldview brings about makes it possible to treat these worldviews as an appropriate subject matter of pastoral theology.

What this living web of worldviews of mothers' illuminates is that none of these worldviews and understandings of disability is sufficient by itself alone. It shows that the phenomenon of disability is opened to be interpreted in many different lights and angles. Just because the content of worldview is theological does not make enough theological understanding of disability to be practiced when seeing from mothers' lived experience. Ironically this limit of theological discussion that mothers' living web of worldview discloses on disability emphasizes the advantages of practical/pastoral theology in its ability to focus on pastoral function of certain idea and theological reflection of caring relationship.

### **Part 3. Multiple Disability Worldviews That Shape Two Mothers' Lived Theologies**

In Part 1, I adapted 'models' of disability to 'worldviews' and explored various components of worldviews and 'community' as a subject of care. Further I argued that a group of people who share worldviews of disability can be interpreted as a 'community.' From that standpoint, they become a community of a worldview, even without a physically based united group, as they line up with Patton's definition of community that we saw in the previous section. Then, I introduced the mechanism of a living web of worldviews. In this section, I will explore Alice and Karyn's narratives to see what specific kinds of worldviews exist. (Explanation of specific kinds of worldviews are in Appendix A. Various worldviews of disabilities) Through this endeavor, I specifically assert that it is possible for mothers to hold various worldviews

simultaneously and argue that this living web of worldviews constitutes significant part of mothers' lived theology.

Alice

The medical worldview, identity-based worldview, cultural worldview, and the limit/restriction-related worldview are all active in Alice's narrative. It is important to note that these worldviews could be observed throughout Alice's narrative, but not necessarily as one neat, organized account. Rather, these prevalent worldviews appear to permeate Alice's story overall. While the medical, identity-based, and cultural worldviews are primarily exercised when Alice tries to make sense of Julius' disability, the limit/restriction-related worldview emerges to function, for Alice, as a perspective when she tries to integrate Julius with people without disability.

In Alice's narrative, the medical worldview is one of the dominant worldviews operating and exerting its influence of her perception of the world and her experiences with Julius. Especially in the beginning, it was strongly explicit in that it shaped many of her thoughts and capacity to understand her circumstances. Then, it continued to exist in her hope of alleviating Julius' disability even when, very recently, Alice began to understand Julius considering other worldviews such as the identity and cultural worldview. This is important as the phenomenon directly shows it is possible to have these kinds of theoretically irreconcilable understandings concurrently. This is something the field of disability theology has thus far failed to acknowledge.

Let me begin with observing the medical worldview imbued in Alice's narrative. Alice's medical worldview of disability is shaped and demonstrated in the following ways: 1. in her

immediate sense of dread she felt when she first faced toward Julius' disability when she first faced her son's disability; 2. in her seeking a "cure" through therapies; and 3. in her hope for Julius to improve his ability to communicate and move. The primary characterization of the medical worldview entails understanding of disability "as objectively bad, as a pitiable condition,"<sup>71</sup> both to "the individual and [their] family, something to be prevented and if possible, cured."<sup>72</sup> This was Alice's underlying assumption of Julius' disability that propelled her to seek out every possible form of therapy in her desperate, and perhaps misguided, hope to find a cure. Recalling how Retief and Letšosa pointed out that the medical model is sometimes referred to as the 'personal tragedy' model.<sup>73</sup> 'Personal Tragedy' is how Alice interpreted what had happened to Julius and herself.

This medical worldview and personal tragedy outlook are prominent in the first section of Alice's narrative. Prior to having Julius, Alice was already familiar with disability because her sister had Down syndrome. However, when she (first) encountered her son's disability, she was deeply struck by a sense of shock, sadness, loss, and helplessness – more than she could have imagined. These feelings have continued. Alice's emotional reaction, to some extent, reveals her deep-seated conception of disability as a tragedy. Her child was diagnosed as suffering from Spastic Quadriplegic Cerebral Palsy (SQCP), "a form of cerebral palsy that means the 'loss of use of the whole body.'"<sup>74</sup> It is known as one of the most severe of the three types of spastic cerebral palsies, "marked by the inability to control and use the legs, arms, and body."<sup>75</sup>

---

<sup>71</sup> Retief and Letšosa, "Models of Disability," 3.

<sup>72</sup> Retief and Letšosa, "Models of Disability," 3.

<sup>73</sup> Retief and Letšosa, "Models of Disability," 3.

<sup>74</sup> Gina Jansheski, "Spastic Quadriplegia Cerebral Palsy," Cerebral Palsy Guidance, updated March 17, 2022, <https://www.cerebralpalsyguidance.com/cerebral-palsy/types/spastic-quadruplegia/>.

<sup>75</sup> Jansheski, "Spastic Quadriplegia Cerebral Palsy."



Shortly after Alice learned of her son's disability, her doctor referred her to another mother of a disabled child in hopes of changing helpful information or encourage each other. In the phone conversation she had with this mother whose child had a diagnosis similar to Julius', how the medical worldview weighed on her mind becomes obvious. While this mother was delighted to see what her kid was capable of, despite her condition, Alice was filled with dejection and contrition because of what Julius could not do. This attitude aligns with the medical perspective of seeing impairment "as a medical problem that resides in the individual. It is a defect in or failure of a bodily system and as such is inherently abnormal and pathological."<sup>76</sup> During their phone conversations, Alice said she sobbed silently because she did not want the other woman to hear her crying. But why did she feel she had to cry silently? Why could she not let the other woman know that she was crying? To Alice, she did not have the heart to share her grief while this mother shared such elation for the things her daughter. Their children were experiencing similar levels of ability and disability, but the women had incredibly *divergent perceptions* of their children's disabilities, which leads them to have *distinct experiences*. In this stage of her life, for Alice, Julius' impairment was clearly interpreted from within the medical worldview, as a reason to feel sadness. Alice said she did not see Julius' disability in the same way that the other mother saw her daughter's because "her daughter could only sit for 20 seconds." Alice closed the sentence with the question which I could not answer, "Does that count?"

The only part of the SQCP diagnosis that was initially clear to Alice was the fact that it meant loss of use of the whole body. Alice had no way to grasp the full meaning of this diagnosis nor any way to express her intense grief. In her interpretation of this tragedy, Alice felt a "deep

---

<sup>76</sup> Retief and Letšosa, "Models of Disability," 3.

sense of loss” within herself. The sense of loss Alice experienced is something that calls for closer examination because, in fact, she did not *lose* her son’s ability. Her son was born with a given degree of ability and inability, a fact that exists beyond her sphere of control. However, her feeling of loss was still very much entrenched in her heart. Then, what is it that she lost? Or that she considered lost? It is her image of her son; normal, without inability, disability-free. In Lester’s language, it is loss of a future story.<sup>77</sup> This, the relentless waves of disappointment and grief, is one of the common phenomena mothers face when experiencing life with their children with disabilities.

That said, although mothers’ immediate responses are similarly observed by Rosalyn Darling and in my research, the difference is that unlike Darling’s observation that their sadness eventually transforms into acceptance, I argue that mothers may develop different kinds of response toward their children’s disability, but their original sadness does not completely disappear nor is replaced with other sentiment(s). Many support groups and a wide breadth of social science literature interpret this grieving process as a method employed by mothers to facilitate and process their situations. Alice, however, was not exposed to any of these support systems and had to navigate her toilsome journey alone as a single mother.

Alice’s conception, that she couldn’t help but to think her son sitting 20 minutes would not count as sitting, evidenced her strong innate medical understanding. As such, because the mother with whom she talked had a different perspective on her own child’s disabilities, when they talked Alice suppressed her emotional anger and grief. She wasn’t able to accept the fact that her son could not sit up; thus, she had to learn to change what it meant to “sit.” She began to create her own definition of “sitting” by questioning things that were familiar to her. This

---

<sup>77</sup> Lester, *Hope in Pastoral Care and Counseling*, 72–84.

activity is related with her identity as an artist. Among many functions, one of the important functions of art is to offer new perspective, “seeing differently” by inviting an audience into the way the artist sees and experiences the world. That is, this is one of the familiar activities of Alice. To make sense of her son’s situation, she asked herself: “What does ‘sit’ mean? How do you redefine it? How do you redefine ‘talking’? What does ‘communication’ mean?” She began to reinterpret the vocabularies with which she was familiar. The terms she had commonly used did not appear to include Julius’ behaviors, and she could not allow Julius to be excluded. Thus, she began expanding reimagining the definitions of some words, including those of fundamental concepts like ‘sitting’ and ‘eating’ as they would fit the situation of Julius.

Alice’s pursuit of medical skills more explicitly represents how the medical worldview operated in her mind and how it determined the value of learned behaviors and abilities. While attempting to redefine her assumptions about everyday activities, she tried every way she could possibly fathom to ‘fix’ the inabilities of her son through multiple, distinctive kinds of therapy. Alice said that, in the beginning, it was mostly out of desperation that she began to explore different forms of therapy. She really wanted to find a cure. In our interview, she said to me, “You want a cure so badly. You want to try every single therapy you can possibly try.”

When a diagnosis like Julius’ is given, mothers are usually introduced to many kinds of therapy through social agency programs, Alice explained. In Alice’s case, basic therapies were included as part of Julius’ care plan. At this point, Alice did not know anything about therapy. A case worker would come and speak to her. Alice would follow the directions given by the case worker. Under the Early Intervention Program, in addition to basic speech, occupational, and physical therapies, Alice would discover other treatments, such as Feldenkrais therapy. In this process, Alice met therapists from alternative or integrative fields of medicine such as reiki and

craniosacral therapy. These alternative therapies sometimes resulted in almost miraculous things happening to Julius. Alice witnessed the positive effect of some of the therapies. Alice continued to have Julius receive these kinds of therapies until recently. Because she believed in their healing effect, Alice invested in a lot of them until two years ago. At that point, Alice began to realize that therapies for children or people with disabilities too often were just a good business.

At the same time, Alice was strongly inclined to believe in the social and identity models of disability. The first evidence of this comes from an incident, a small social interaction at the grocery store, that results in a heartbreaking experience for Alice. As we have seen that the social worldview was generated as a response to the medical worldview, similar dynamics are observed in Alice. It was when Julius was yet a baby, his disability not being so apparent. When the cashier noticed something different about Julius and asked naively, “What’s wrong with him?” Alice felt a deep sense of dread. Alice already had a history with that sort of comment from people. It was what she would frequently hear when she was with her sister. She did not want to answer that question because she was concerned about labeling Julius. She was upset just hearing that naïve question from the cashier because Alice was worried that Julius might understand that question and begin to think “something is wrong with me.” Alice did not want Julius to ever think anything was wrong with him. Alice knew that people have the tendency to make judgments that if other people are not like me then they are “wrong.” Alice said that was the moment she knew that Julius was whole in his own way and she had to be there for her son and to make him understand “that there’s never anything wrong with him, even though his body and his life and his way of interacting with the world are different from ours, they are not wrong.” In uttering this sentence, Alice looked unwavering and resolute. Alice’s sense of an

identity worldview was revealed as a reaction when an unknown person was explicitly looking at Julius from an apparent medical, personal tragedy perspective.

Similarly, disability to Alice was an element of difference that keeps people interesting to and learning from each other, which I see as a logical result of the identity worldview. To see a person's disability as what makes this person different and unique is possible when a person's disability is not considered a problem. It also signals that a process of acceptance has begun for Alice. Having different abilities and disabilities is what makes people different and thus able to learn from each other. Alice learned that it is possible for people to learn from each other when they are differently abled. She continued:

We can talk until we're blue in the face. We can tell people how they are supposed to act and how they're not supposed to act and what they are supposed to confess to and what this means. We need people to live and work together. Then they don't get bored. When people are not bored, then it's like an "Aha" experience. That happens to Julius all the time.

This identity worldview became more explicit, a goal to passionately pursue, for Alice when it materialized into an art workshop for children with disabilities called KS (Kindred Spirits) Studio which has featured in media.<sup>78</sup> Her agenda for her child became a part of her career. The art studio in Utah that Alice decided to create for her son and for other children with disabilities is a prime example that concretizes the identity model in Alice's lived experience. Children with various kinds of disabilities are welcomed into this program. The rule in this program is that the child has to actually participate in the project, which means that any assistance offered is only to help the child find a way to accomplish the project. Children unable to use their hands, have the material attached somehow to their bodies. For this reason, Alice and

---

<sup>78</sup> Peter Rosen, "Inspired by Sister and Son, Woman Creates Unique Art Experience," *KSL Broadcasting Salt Lake City UT*, June 24, 2011, <https://www.ksl.com/article/16113115>; "KS Studio—Kindred Spirits," Alice Marie Perreault, <https://www.alicemarieperreault.com/ks-studio.html>.

her colleagues prepare little tools made with plastic holders to which things like pencils and brushes can be attached so that children who cannot use their hands and fingers can use these tools to engage in art activities. This has helped children to find their own ways to use their bodies to enable them to draw. Children have found they can use an elbow, arm, or leg to create something. There was a previous experience that catalyzed Alice to think of this project. When Julius was in school, after the class Julius would bring a craft that was apparently made by someone other than Julius, because it was beyond what Julius could accomplish. The craft Julius brought was well-made, but it was not made by Julius. Seeing those crafts, Alice knew that Julius was excluded from the activities mostly designed for normal kids. Alice said, “it was made by teachers.” For this reason, it was important and meaningful to Alice that children do not look to teachers to get help but focus on their own work and what they can do. When children with disabilities could say, ‘This is my work,’ Alice felt empowered and proud to provide the space where it could happen. Alice said, when you get to say “Hey, this is Julius’ work, it was very, very empowering to create a space like this.”

The cultural worldview, closely related to the identity worldview, was also observed in Alice’s narrative. The cultural worldview sees disability as culture. It resists defining disability in a specific way, unlike the medical and the social worldviews. Rather, the cultural worldview “focuses on how different notions of disability and non-disability operate in the context of a specific culture.”<sup>79</sup> Alice, in fact, from the beginning, attempts to see Julius’ own “culture” when she questioned and reexamined the vocabularies she had used. Alice did two things: she began to carefully observe Julius, and she adjusted or revised the meaning of the terms and social conventions she already knew, such as “sitting,” and the way people express and share affection

---

<sup>79</sup> Retief and Letšosa, “Models of Disability,” 6.

with each other. After the phone conversation Alice had with another mother that I introduced earlier, Alice asked herself, “What does ‘sit’ mean? I had to redefine a whole set of words.” In the beginning, she didn’t consider Julius’ sitting for five seconds as “sitting.” At the same time, Julius’ apparent disability to sit wasn’t acceptable to her, which ultimately led Alice to question the word, ‘sitting.’ Alice, while living with and caring for Julius, learned that she cannot expect from Julius what she would expect from a so-called normal child. This was a part of the learning process for Alice as she adjusted to Julius. She began to look for and see Julius’ own way of communication and adjusted herself into Julius’ culture.

Alice also appears to employ the limit worldview, which considers “disability” a fundamental and inevitable experience of human beings. This is evident in Alice account,

I now understand that everybody has a disability. Right? I had not thought about that before. There was a separation between people with disabilities and people without disabilities. *That separation does not exist anymore. Everybody has a disability; everybody has a limitation.* A lot of disabilities are self-imposed, because of our upbringings, because of people who have been told negative things throughout their lives. And so they are psychologically handicapped—they can’t move over, they can’t get past something. Other handicaps are apparent, are worn on the outside. *But everybody lives with a disability;* so when you are feeling sorry for me, I always think: take a look at yourself. What makes you think that we are sorrowful? Why can’t you see that we’re spectacular? [Italics added]

Alice’s statement mostly aligns with the limit worldview proposed by Creamer. Creamer proposes the limit model out of the frustration she experienced through the social model. She saw that the social model of disability was becoming too exclusive because its tendency was to emphasize the experience of exclusion resulting from the identification of disability. For Creamer, this could be an act of drawing a line between people with disabilities and those without disability or those whose identification of disability is not so clear, just like Creamer herself.<sup>80</sup> Turning our focus to Alice, in this remark I see her doing two things. First, disability

---

<sup>80</sup> Creamer, *Disability and Christian Theology*, 8.

becomes a framework within which she understands human beings. In this sense, the meaning of disability goes beyond the specific disabilities we know through medical terminology. Instead, it is being interpreted more as “limit” in its most general sense that is very similar with Creamer’s understanding of limit. And through expansion of meaning, the term ‘limit’ now has the ability to neutralize the negative tone implied in the term, disability. If all people are somehow disabled or will be disabled at some point in their lives, it could not be too bad. Second, we can observe that one of Creamer’s goals in proposing the limit model is exactly achieved in Alice’s lived experience: weakening the boundary between people with disabilities and people without disabilities. Alice was using the limit worldview to position Julius and all other people in the same category: that of a human being. “Disability” here is less of a medical condition and more of a fundamental human experience that people can share and through which they can understand each other. Through the use of the limit worldview, Julius with his disability was no different than other people.

As such, I have shown that as Alice’s narrative unfolds, increasing elements of both the identity and limit worldview are evident, and even with this, there are elements of the medical worldview still operating in her narrative. How can we know that? We can infer that by exploring Alice’s current hope as Alice’s hope for the future reveals elements of the medical worldview underneath these more explicit models. The nature of this hope aligns with the worldview model of disability in the sense that what Alice hopes for is the improvement of Julius’ physical and mental condition. Alice said,

Our biggest hope right now is for Julius to master two things, and it’s very slow, but he recently.... We’ve been working with an eye gaze communication device, because I want him to be able to communicate with people, I want people to understand he’s a person in there, and right now his intelligence and understanding are always underestimated. People just say, “Oh, that’s okay.” He gets talked around as if he’s not there. So his being able to communicate changes everything. If you have a method of



communication, it changes your relationship with the world. So that is a big hope. My second hope is mobility, although that one makes me a little nervous [chuckle]. Because other parents I know whose children became mobile with their power chairs, all of a sudden also became defiant. “Get back here.” “No.” But No, and then the mobility is the other one. So those are my two.

So far we have confirmed that Alice’s narrative reflects the medical worldview of disability that occupied a substantial portion of her early narrative. Her later-developed identity, cultural, and limit worldview do not completely dissolve the medical model. The ending of Alice’s narrative, which strongly emphasizes hope, indicates that aspects of the medical worldview of disability continue to operate. These seemingly contradictory worldviews do not function in a mutually exclusive way. Rather, in Alice’s narrative, the medical worldview, the identity, the cultural and the limit worldview were all observed to exist together, layer upon layer.

Now that we have explored Alice’s narrative through the context of various worldviews, we see that Alice’s story does not follow the ‘dominant narrative’ of parents who gradually learn to accept the disability of their child proposed by Darling. According to the dominant narrative, one model replaces another. This disregards the fact that parents may have multiple orientations on disability at the same time. Looking from the perspective of mothers’ experiences, the ‘dominant narrative’ is too simplistic a phrase in that it suggests that parents experience a separate model in each phase, moving from one model of disability to another. The complexity of mothers’ lived disability theology lies in the fact that the different worldview of disability can overlap. One worldview does not replace the other or erase earlier understandings. Different understandings of disability can live together; thus mothers’ stories become more complicated as they develop understandings of disability that are contradictory to those presented in disability theology literature.

Karyn

Three worldviews were evident in Karyn's narrative: the medical worldview, the identity worldview and the moral and/or religious worldview. In Karyn's narrative, the medical worldview of disability appeared predominant, more so than in Alice's narrative. However, there were moments when Karyn employed the identity worldview and the moral/religious worldview. One of the reasons the medical model of disability is more directly revealed and explicit is because Karyn's living human web included both personal and professional contexts that are themselves medically oriented. Karyn is surrounded by family members who have jobs in medical fields, and she herself is a chief of occupational therapists in her hospital. Three themes demonstrate Karyn's medical worldview. First, her emotional response to the doctors' diagnoses of Corbyn's disability revealed the medical worldview she ascribed to disability, Second, her investment in the field of therapy, including the endless therapies Karyn had Corbyn receive and the fact that she herself became a therapist for her daughter. Lastly, the response from social media—all these contributed to construct, support and strengthen Karyn's worldview of the medical understanding of disability.

Let me begin with Karyn's background. As we read in Chapter 4, Karyn wasn't afforded a chance to establish a relationship with the notion of disability before she met her daughter. She said she knew nothing about disability. However, this is not completely accurate. More accurate is that she was exposed only to the medical perspective of disability. We also know that Karyn grew up in a family comprised of physicians, including her father and siblings. Being in the medical field does not necessarily mean people hold on to the medical worldview of disability.

However, in the case of Karyn, the influence of the medical worldview was evident in her assumptions, philosophy and value.

First, Karyn's immediate response to Corbyn's disability reveals, in a way, the implicit meaning Karyn has ascribed to the notion of disability which, fundamentally, congruent with the medical worldview of disability—that it is a 'deficit' and a 'failure.' From this perspective, it is reasonable that her response consists primarily of shock, fear, a sense of dread, and desperation to the point that the experience became a trauma that took seven years for Karyn to overcome. As with Alice, to face her child with disability, especially in the beginning, was experienced as 'personal tragedy' for Karyn. Conceiving disability as personal tragedy was one of the integral elements of the medical worldview of disability.<sup>81</sup> Karyn's narrative begins with her personal and intuitive sense, which she felt clearly but could not describe. She somehow knew something was approaching her, and it was not a pleasant feeling. Because of this feeling, she brought her daughter Corbyn to see doctors several times. However, doctors repeatedly told Karyn that Corbyn had no issue, that there was nothing to worry about. Karyn didn't believe her doctors, just as the doctors didn't believe Karyn. Karyn said, "I knew there was something wrong with her, but of course, I didn't know what it was." She could not be clearer about remembering the exact date of the attack. "On January 19th, 1989, she [Corbyn] had a bleed, and with that bleed, came a grand mal seizure."<sup>82</sup> She had said the same thing to her mother, who in return offered to take care of Corbyn while Karyn was attending her photography class because Karyn said she planned to miss the class because of this strange feeling about her daughter. Karyn resisted her mother's suggestion because she knew "something very bad is gonna happen today, and I'm not

---

<sup>81</sup> Retief and Letšosa, "Models of Disability," 3.

<sup>82</sup> In my pilot research, there is a strikingly similar narrative told by another mother of instinctively knowing and feeling that "something is wrong" with her child before her child's problem is diagnosed.

gonna leave the baby.” Persuaded by her mother’s insistence that nothing bad was going to happen, Karyn went to school. However, an hour later, “all of a sudden” she felt “this overwhelming sense of dread, literally. The most horrific feeling ever, and I start to shake, and I’m really scared.” She lived only ten minutes from the school. Immediately after she had that dreadful feeling, she got in the car and drove home. “As I’m approaching the apartment, I’m literally shaking violently, I’m so afraid of what I’m gonna find when I open the door.” What she found was a baby “just all white, even her lips, which normally have a very bright red color to them.” As Karyn got home, the seizure ended but then Corbyn immediately began “vomiting, technically, but because she lost all sphincter control with the seizure, she was also having a bowel movement and urinating at the same time she was vomiting. I turned her onto her stomach and she’s vomiting all over the apartment. And of course. I called the doctor.” It was a moment when everything Karyn worried about became reality.

This was the beginning of Karyn’s experience of Corbyn’s disability, and this experience caused a trauma that Karyn would suffer for the next seven years. Karyn remembers every minute of what happened on January 19, 1989, the day of Corbyn’s seizure. She said, “There’s no way to forget that. I had pretty severe PTSD on that date, and for years I relived the trauma every January 19th. Corbyn was probably seven years old when I stopped panicking on that day.” Because of this, Karyn had to be with Corbyn every January 19, and on that day Karyn became “pretty panicky and unhappy. It was never nice.” After seven years, she didn’t have, in her words, a “freak attack” anymore. Currently, Karyn doesn’t think about January 19 at all. She said, “Of course, it’s now, 31 years later. Took a long time for me to get over that. A long time.” Karyn laughed with a sense of relief.

The fear continued for Karyn until she had her second child, Aaron. Karyn repeatedly dreamed that her new son Aaron, who has no disability, would drown. This fear of losing her second child made her particularly sensitive about not having a swimming pool at home when she was considering moving.<sup>83</sup> The fear subsided after a while and finally Karyn was able to let Aron learn to swim. This shows the extent of the emotional impact of Corbyn's disability and its lasting effect on Karyn. It is notable that Karyn's emotion of fear, and the shock she felt, as well as the fact that the fear and shock were not tended to.

In Karyn's traumatic responses to Corbyn's disability and through her interpretation of it, we can also identify the influence of the moral and/or religious worldview, which interprets disability as an act of God. We have seen that Karyn's response entails the medical worldview in that Karyn understood disability as "damage," "punishment," and "a bad life." Karyn was making a value judgement on a specific human condition, in this case, Corbyn's disability from the medical worldview. Interestingly enough, while Karyn identified herself as neither religious nor spiritual, the moral and/or religious worldview that sees disability as an act of God even in a negative form, was also identified in Karyn's narrative. Karyn's voice rose and her shortness of breath was observable while she was explaining this:

I don't have any sense of religion at all. When I was going through all of this stuff with my daughter, a lot of people would say things to me like, "God doesn't give you more than you can handle," and, "You're strong," and "You can do this." And I would just roll my eyes and say, "There's clearly no God, there's clearly not. There's nothing like that, there can't be," because if there was something like that, then they'd never have harmed this innocent baby. To make a baby born like this, a baby who has these problems may not survive, will be disabled and have a bad life. That makes no sense. If there's some kind of punishment that's to be had, the punishment should be dealt to me and not to the baby who did nothing. So to have a baby born with a congenital anomaly, like the aneurysm that ruptured and caused the severe brain damage, it's not fair to her. And it just makes no sense. I had no religion before and, if anything, this cemented the fact that there is absolutely nothing like that.

---

<sup>83</sup> This pattern reveals the tendency to seek reasons that will justify human emotions.

The essence of a moral and/or religious worldview is to believe that disability is an act of God. Attributing the cause of disability to an ultimate being, to some degree, stresses the uncontrollable nature of disability. There are two ways to attribute a cause to God: one is as an act of punishment; the other one is as an intended obstacle for character or faith development. Karyn was employing the first one; disability as a punishment by God. Because this assumption does not make sense to Karyn, this explanation became a reason for Karyn to turn all together from Christianity. Her use of the moral and/or religious worldview was to justify the reason why she doesn't believe in God. It is important to note that this piece of information about the nature of God influenced her decision not to believe in God.

Retief and Letšosa points out that this worldview “perpetuates the myth of disability as mysticism or some kind of metaphysical blessing.”<sup>84</sup> The logic here is to ask God for blessing or forgiveness because the cause of disability, whether it's an obstacle or a punishment, is in God. Karyn neither diagnosed the disability as God's action nor asked for God's help. She thought if there is anything that needs to be done, it's her job. This is how Karyn choose to respond: I think that it's amazing for people, after something bad has happened, to say that ‘God will save me and help me and will heal me’ and will, whatever, of course. I just think in my head, ‘Good luck with that. Not gonna happen.’ So if it was going to happen, then I would have devoted my entire life to trying to fix my daughter, and you can't undo profound brain damage.

Both worldviews Karyn showed—the medical worldview and the moral and/or religious worldview—view disability as “something bad.” That is, biological impairment is something negative and fundamentally in need of correction, repair; Karyn sees it as that which prevents the notion of “health.” Karyn's conception of disability, as stated above, shows a correlation with the

---

<sup>84</sup> Retief and Letšosa, “Models of Disability,” 2.

way she, as a professional speech therapist, looks at and treats disability. Karyn is a speech/language pathologist, working in a hospital. Karyn's job as a speech/language therapist is one of the most important identities for Karyn. Karyn had always thought she would be a physician one day but "after all these things about my daughter happened" she wanted to be a therapist for her daughter. While taking care of her daughter, Karyn observed that therapists have more meaningful relationships with patients than do doctors. Karyn became a "mom therapist" in Karyn's words. Betterment or improvement means precisely that her daughter is becoming a person with the least level of disability as measured in the medical/economic model. Karyn's goal is for her daughter to be able to advocate for herself.

The medical understanding of disability is also deeply rooted in the field of occupational therapy. Historians trace the origin of occupational therapy in the moral movement in England as a way to improve the ill treatment of mental health patients in England, France, and the United States in the early nineteenth century. For example, in the early nineteenth century, the difference between the medical service provided to the rich and the poor was stark. The rich person could have a private physician attending at home or a private madhouse, while those who could not afford private medical service would "most likely to be treated no differently from other social deviants, being classed with the destitute, vagrants and criminals."<sup>85</sup> Even some mental health patients "were incarcerated in prisons, workhouses or in one of the few hospitals for pauper patients, such as Bethlem Hospital in London."<sup>86</sup> These kinds of institutions used physical restraint with manacles and chains and had "usually no heat or lighting, little food, clothing, bedding or sanitation, no segregation of the violent from the quiet and withdrawn, and

---

<sup>85</sup> Catherine F. Paterson, "A Short History of Occupational Therapy in Psychiatry," in *Occupational Therapy and Mental Health*, ed. Jennifer Creek and Lesley Lougher, Occupational Therapy Essentials, 4th ed. (London: Churchill Livingstone, 2008), 5.

<sup>86</sup> Paterson, "A Short History of Occupational Therapy," 4.

no meaningful occupation.”<sup>87</sup> The moral movement was a response by psychiatrists, public figures, and intellectuals to reform these mental illness institutions and systems with humanitarian principles: to attend to the psychology of patients rather than only physical treatment<sup>88</sup> and to improve the quality of life of mental health patients. The institutions began to include elements of mundane human life such as outdoor recreation, working, gardening, gathering, cleaning, and such. This was the antecedent of what later became occupational therapy.

It was at the end of the nineteenth century when occupational therapy began to be considered a medical profession in the United States as well as in Britain.<sup>89</sup> Adolf Meyer (1866–1950), a physician, is generally considered one of the founders of the field of occupational therapy in the USA who immigrated from Switzerland to America in 1892. During this time, Meyer asserted that “the proper use of time in some helpful and gratifying activity appeared to me a fundamental issue in the treatment of any neuropsychiatric patient.” His wife—who was a social worker and shared his belief in the therapeutic function of engaging in occupations—introduced activities into the system of the state institution in Worcester, Massachusetts.<sup>90</sup> Meyer and his wife worked with colleagues<sup>91</sup> in establishing directed occupation as a mean of therapy within the medical services. Within this group, the term ‘occupational therapy’ was first introduced at a meeting in 1914, and the Promotion of Occupational Therapy was formed soon after, which is now the American Occupational Therapy Association.<sup>92</sup> While occupational therapy explicitly focused on participating in mundane activities of life and rehabilitation, the

---

<sup>87</sup> Paterson, “A Short History of Occupational Therapy,” 4.

<sup>88</sup> Paterson, “A Short History of Occupational Therapy,” 4–7.

<sup>89</sup> Paterson, “A Short History of Occupational Therapy,” 8.

<sup>90</sup> Paterson, “A Short History of Occupational Therapy,” 8.

<sup>91</sup> Paterson, “A Short History of Occupational Therapy,” 8. The colleagues were Susan E. Tracy, a nurse, Eleanor Clarke Slagle, a social worker, and William Rush Dunton Jr., a psychiatrist.

<sup>92</sup> Paterson, “A Short History of Occupational Therapy,” 8.



field is still largely considered under the umbrella of the larger field of medicine.<sup>93</sup> The two disciplines share the most essential assumptions about the normal and abnormal human condition, body, and way of life; these assumptions decide the goal of treatment.

For Karyn, the task of mothering largely involves the work of herself as a therapist. Karyn said she has been ‘a mom therapist,’ and the very reason she became a therapist was to be a personal therapist for her daughter. Besides, Karyn said that she thinks of herself more as a therapist than as mother to her daughter. It is interesting that Karyn draws this distinction between therapist and mother as if there *is* a difference. What is implicit in her remark is that an occupational therapist’s role is to support and advocate for patients with a specific goal—that is, for Corbyn to improve her ability in everyday activities—whereas a mother does not intend to “change” her child as much as the therapist does. Karyn, to some degree, personalized her professional identity and role by seeing it as mother’s work, and this demonstrates the prevalence of the medical worldview that Karyn held functioning in both private and public arenas of her life. Yet, in both areas, Karyn’s goal for Corbyn was clear as she strove to mediate her daughter’s disability.

When Corbyn was 12 years old, the article “A Mother’s Love, A Daughter’s Courage” was published in the *Tampa Tribune*, featuring Corbyn and Karyn.<sup>94</sup> The article was published to celebrate Corbyn being picked from hundreds of people to carry the Olympic torch as one of “the people who inspire us and bring us together.”<sup>95</sup> The article supported and strengthened the medical worldview of disability, especially in two ways: 1. By depicting Corbyn and Karyn’s story as overcoming personal tragedy and 2. by praising Corbyn’s achievements as a source of

---

<sup>93</sup> The interaction of the field of occupational therapy and rehabilitation medicine in the early twentieth century reflects the commonalities of these two fields.

<sup>94</sup> Peterson, “A Mother’s Love.”

<sup>95</sup> Peterson, “A Mother’s Love.”

inspiration. The general structure of the narrative follows the structure of a “triumphal narrative”<sup>96</sup> by beginning with “the tragedy” that happened to both Corbyn and Karyn when Corbyn was three years old. It gradually develops this theme by addressing the efforts that Karyn has made for Corbyn to cure her illness and improve her body condition. The anchor of the story is Corbyn’s embodiment; the more Corbyn becomes functional, the more replete with a positive mood is the story. The disability is individualized as personal tragedy, described as an “obstacle” to be overcome and resolved. This kind of narrative is not without a problem that rather harm, unlike its intention, to see the agent of people with disabilities.

For instance, comedian Stella Young, a person with a disability who used a wheelchair, who was a disability advocate, astutely points out the problem of objectification in this kind of narrative. She argued that this kind of inspirational and motivational speech was an injustice for those who have disabilities. In her Ted Talk in 2014, she shares her experience of being nominated for a community achievement award. She also shares her parents’ joking response to the nomination committee: “Hm, that’s really nice, but there’s kind of one glaring problem with that. She hasn’t actually achieved anything.”<sup>97</sup> In fact, she said, she was simply living her life by doing ordinary things that would not be considered an achievement if the word “disability” was taken out of the equation.<sup>98</sup> From this perspective, saying, “You’re an inspiration,” which was meant to be a compliment, is, in fact, objectifying and exceptionalizing a person with disability and will only benefit nondisabled people by providing source of comfort. In Young’s words, “They are there so that you [nondisabled people] can look at them and think that things aren’t so

---

<sup>96</sup> Hur, “The Stories of Parents,” 47–62.

<sup>97</sup> Stella Young, “I’m not your inspiration, thank you very much,” TED talk, [https://www.ted.com/talks/stella\\_young\\_i\\_m\\_not\\_your\\_inspiration\\_thank\\_you\\_very\\_much/transcript?language=ab](https://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much/transcript?language=ab).

<sup>98</sup> Young, “I’m not your inspiration.”

bad for you, to put your worries into perspective.”<sup>99</sup> It is one of the popular perspectives that does not reflect the reality of people with disabilities because it fails to regard them as equal to nondisabled people.

Karyn’s understanding of disability becomes more complex, and thus it is difficult to simply pinpoint one worldview, when changing the perspective to closely observe the interaction between Karyn and Corbyn. On one hand, Karyn is firmly holding the medical worldview. For instance, Karyn said Corbyn is “fantabulous” because Corbyn is able to do many things. Karyn said, “the doctors told me she’d never walk, and she wouldn’t talk and she’d have a feeding tube and be in a wheelchair; that the brain damage was just too severe. And my kid drives a car, she graduated from college. All that took a long time. And she would tell you that I’m mean. Her entire life was therapy.” The logic behind this statement is that Corbyn is fantastic because of the things she “does.” Here Karyn’s narrative reveals the predominance of the medical worldview of disability, which almost aligns with the way the *Tampa Tribune* framed Karyn’s and Corbyn’s story in that both Karyn and the *Tempa Tribune* focus on Corbyn’s achievements.

However, besides the medical perspective, we can see the element of social worldview, in addition to the medical diagnosis and Social Security benefits, clearly influencing and shaping Karyn’s understanding of disability. Let’s look closely at what Karyn explicitly thinks of as disability: “I guess I consider anything a disability, that is not normal in society. So technically somebody with a disorder verbal fluency can legally be labeled as disabled, which is fascinating to me, because I would never consider a lack of fluency to be a disorder. I don’t know—my definition, my technical—I-guess—working definition is that a disorder is anything that is abnormal in society and therefore, hinders some aspect of that person’s life.” This definition,

---

<sup>99</sup> Young, “I’m not your inspiration.”

however, does not apply when it comes to the moment when Karyn thought of her daughter as part of the relationship the two of them share, especially when Karyn saw Corbyn internalizing the medical worldview to understand herself. For example, Karyn said Corbyn labels herself as disabled, and Karyn would tell her that she's just differently-abled. Karyn continued,

That was always my take on it. In fact, she's not normal, she can't be normal, she doesn't. . . . She's missing almost half of her brain. She gets disability insurance, and the state says she's disabled. She can't work because she has some cognitive inflexibility, where it'd be really difficult. . . . [chuckle] it would be really difficult to multi-task and follow rules. Like when your boss asks you to do something and you may or may not like your boss. It doesn't matter, you can't yell at them, you just simply say yes, and you go do it. That kind of thing, she could never do. Pragmatically, she would not. She would yell, she would yell at them, or she would. . . . It just would not work, So yeah, she gets disability. Although I think she could do anything if she really wanted to, and that's the key, because she can do just about anything she wants to do, but she has to truly want to do it, it has to have some personal meaning to her, you know what I mean?

Karyn's use of the term "differently-abled" requires deeper reflection. According to the "Disability Language Style Guide" published by the National Center on Disability and Journalism, "differently-abled" is the term that began to be widely used in academia and disability activism in the 1990's as an alternative to terms such as "disabled," "handicapped," or "mentally retarded"<sup>100</sup> as an effort to avoid the negative connotation of disability. However, despite its intention, the use of this term has experienced backlash from people with disabilities in that people experienced this term as a way to avoid talking about 'disability.' Besides, the term 'differently-abled' is condescending because it ignores the differences and complex realities of people with disabilities. It is exactly this 'condescending effect' that I think made it a useful tool to help Karyn understand Corbyn. Because of its condescending effect, the existence of Corbyn's disability could be minimized, which enabled Karyn to put Corbyn in line with other 'normal' people. In other words, the term allowed Karyn not to exceptionalize Corbyn but to

---

<sup>100</sup> "Disability Language Style Guide," *National Center on Disability and Journalism*, August 2021, <https://ncdj.org/style-guide/>.

think of her as part of the larger community that encompasses both people with disability and nondisabled people, because it understands that Corbyn's disability is just one among many.

Karyn's use of the term 'differently-abled' can also be understood as the identity model of disability. Karyn further explained:

And to me she is special in a good way, not a bad way. She's just different. She's not like everybody else, and to me that makes her special. But I would give my life in a heartbeat to make her life normal, because she does not want to be the way she is, she doesn't like it. It's hard when you see your brother who is five years younger than you. Obviously, she graduated high school first because she is older than he is, but for college he graduated before she did, 'cause it took her 10 years to get an undergrad degree. But he graduated in four, like the normal person. And he had his master's degree when he was younger than she is. So I always tell her, 'You could get a master's degree too if you wanted to.' And she's like, 'Why would I want that?' And I'm like, 'I don't know. You could. . . . Then everyone can have a master's degree.' And she's like, "So?" I'm like, "Okay whatever." [chuckle] So other than that, I am not sure what else to give you on that one.

Karyn's use of the notion of "Special in a good way" and "special in a bad way" encapsulate two different ways to respond to disability. "Special in a good way" refers to the identity worldview, whereas "special in a bad way" refers to the medical worldview. Here, we can see the identity (affirmation) worldview operating in Karyn's narrative, especially when she refers to her daughter within their intimate relationship.

Through these narratives, Karyn shows that the major worldviews she is using—especially in her relationship with Corbyn—are the medical and identity understanding of disability. The example of using the medical worldview was having Corbyn receive multiple therapies and Karyn becoming 'a mom therapist' herself for Corbyn. The identity worldview is used in their present relationship, especially when Karyn thinks of Corbyn and to express her gratitude and love toward Corbyn.

To better understand Karyn's identity worldview of disability, there are few people more important in Karyn's narrative: her husband and her father. These people fit the identity

worldview, rather differently with the previous cases. They fit the identity worldview by embodying the identity worldview through their acceptance of Corbyn's disability. The acceptance and acknowledgement even include Karyn's effort that is driven by the medical perspective. Let me begin with Karyn's husband. When Karyn became a single mother busy taking care of Corbyn, Karyn began dating her now-husband, and they soon found themselves bathing Corbyn together when Corbyn was two years old. Karyn's husband legally adopted Corbyn. For Karyn, it was a loving gesture to accept Corbyn as she was. From this, Karyn also felt accepted.

In her narrative, Karyn's father is more explicitly described. Karyn's memory of her father, who was 'the number-one person' in her life, serves as representation of the identity understanding in her narrative. Karyn's father consistently reminded Karyn that Corbyn is fine as she is. For example, when Karyn felt it was easier for her to be the therapist for her daughter than to be her mother, Karyn was ready to be a drill sergeant for Corbyn. She said, "Being a therapist was an easier role and a better role for me." This is because if Karyn set her mind on a certain thing she desire to fix, she "got it fixed." This includes, Corbyn's disability. This switch, from a mother to a therapist, occurred when Corbyn was in sixth grade and reading at a second-grade level. "Corbyn was doing very poorly," said Karyn. Karyn began to hire tutors, "lots of tutors." At the time, Corbyn's schedule was: "she would go to school, and then she would have tutoring four days a week." Karyn paid a lot of money and she tried different people and different companies and "different whatever... to try to help." When things did not go as she expected, she would, say disappointedly, "I don't know if she'll ever. . . . I don't know what she'll do. I don't know, I don't know what she's gonna be able to do." Then her father would say, "Karyn, why do you try so hard? Why can't you just accept her for what she is and love her for what she

is?” Karyn answered, “Because I know I can make her something else. I want to help make her as close to normal as I can.” Karyn continued, “I thought that it would help her. I thought that it would improve her, and I knew that I could do it if I tried hard enough. So when the tutoring was failing, I talked to my supervisor and said I needed to adjust my work schedule; but I would see all my patients. And then I would come home, pick Corbyn up from the bus, and then I would work with her for three to four hours.”

Similar episodes occurred where Karyn’s father reminded Karyn to see Corbyn through the identity perspective. Karyn was determined that Corbyn would be able to progress with any of her peers at school. At home, Karyn made Corbyn exercise, clean her room, and make her bed. Karyn said, “She didn’t have a hall pass for life. If you expect a lot from a child, they’ll give a lot.”<sup>101</sup> Karyn’s father disagreed with Karyn’s determination.<sup>102</sup> Karyn’s father said, “You push too hard. Let her be. It’s enough that she’s alive. . . . Whatever she does, she’ll make her own world.”<sup>103</sup>

The perspectives on Corbyn held by Karyn’s husband and father are most similar to the identity understanding of disability because without negative judgement both of them see Corbyn’s disability as part of Corbyn. For these people, Corbyn’s disability wasn’t necessarily good or bad; discerning how good or bad, valuable or unnecessary was out of their concern. What was most important was that Corbyn’s disability is part of Corbyn herself.<sup>104</sup> It is interesting that Karyn didn’t include stories of how she responded to these words. What was

---

<sup>101</sup> Peterson, “A Mother’s Love.”

<sup>102</sup> Peterson, “A Mother’s Love.”

<sup>103</sup> Peterson, “A Mother’s Love.”

<sup>104</sup> Furthermore, from a slightly different angle, what Karyn’s father affirms applies not only to Corbyn and Corbyn’s disability but also embraces Karyn.

certain is that her father was “a number one person” in her life and that she was a “Daddy’s girl.”

So far we have understood the meaning of the concept of “living web of worldviews” in Part A and explored how this notion of “living web of worldviews” interplay in the narrative of Alice and Karyn in Part B. In Part C, we will examine what kinds of benefits and functions these different worldviews bring into mothers.

### **Pastoral Theological Interpretation: Function of the Worldviews in Mothers’ Lived Theology**

In this section, I will point out the functions of major worldviews—theological, limit-based and the medical—employed by both Alice and Karyn and analyze what kinds of function and benefits these worldviews brought to mothers. Let me begin with theological worldview of disability. Theological worldview was employed and described by mothers in the most experiential way and is the best effective, most emotionally effective source of support. The way Alice and Karyn experience theological worldview of disability is quite different. Karyn experienced the full acceptance of Corbyn through her husband and her father as I shared the related anecdotes above. Her husband when marrying Karyn adopt Corbyn and took the responsibility of caring for Corbyn together with Karyn. Karyn’s father at times gave wise words of full acceptance when Karyn was trying hard to make Corbyn ‘better.’ For Karyn, Ryan and her father, who embodies theological understanding of disability, were the best source of support.

Interestingly enough, for both Alice and Karyn the identity-based worldview of disability was one of the worldviews that they consciously think as the way they understand disability. The



detailed anecdotes were shared in the previous section. To refresh, when I ask directly how they conceive as disability both of them mentioned the identity-based worldview. It seems, to me, that identity-based understanding of disability is one of the most ideally humanistic understanding of disability. The effect of the limit worldview is to realize and emphasize the inclusivity and sense of belonging as community.

When Karyn saw Corbyn identifying as being disabled, Karyn even persuaded her by saying, “Corbyn labels herself as disabled, I always would tell her, ‘She’s just differently-abled’.” However, their narratives, as we have explored, show that the limit-based worldview is not the only worldviews mothers have.

In the previous section, among many different worldviews on disability, the medical worldview was particularly prominent and consistently observed throughout the narratives of both Alice and Karyn. Why is that so? In this section, I attempt to provide answer as to why the medical worldview cannot help but pervade in both of their narratives by identifying the concrete sources of care these mothers gain that are often provided by the community of worldview of disability.

The reason the function of the medical model of disability is particularly pertinent to my dissertation is because this is the point that directly relates to the gap observed between the literature of disability theology and mothers’ lived disability theology, which is the primary question of my dissertation. This reality that medical worldview of disability, for both Alice and Karyn, was no doubt predominantly influential—is what disability theologians would discourage. For disability theologians, the medical understanding of disability has been considered in need of correction due to its limited capacity as a theory to understand and represent the wholeness of a human person and because its application can result in disrespectful

treatment in the context of ministry or caregiving.<sup>105</sup> For this reason, disability theology has favored the social model of disability over the medical model of disability. In doing so, to some extent, disability theology has contributed to the creation of a dichotomy between the social model of disability and the medical worldview of disability, which has resulted in less attention being paid to the positive functions of the medical worldview. From this perspective, mothers' engagement with the medical worldview of disability cannot be fully acknowledged or affirmed. This, in clinical/ spiritual care context, easily results in discouragement of medical worldview and lack of understanding or affirmation on mothers' engagement with the medical worldview or at best oppression to mothers.

However, for mothers like Alice and Karyn, even with these limitations that theologians have pointed out, the medical worldview appears to have many positive aspects from psycho-spiritual, social and pragmatic perspectives which I will unfold from now on. The first five elements mostly relate to mothers' psycho-spiritual aspect. The sixth one is social and the last one is about pragmatics.

First, the medical diagnosis provided a source of validation of these mothers' subjective experiences of their children seeming different. The medical worldview of disability is one of the most dominant and influential discourses used to reference the extent of both physical and mental disability. It is used to communicate the physical symptoms, and the current state and progress of, children, based on—and becoming, in and of itself—a scientific paradigm.<sup>106</sup> In our reality, the medical worldview permeates, informs and influences the major social institutions such as hospitals, the Social Security Administration, and non-profit-communities. Just as these

---

<sup>105</sup> Swinton, *Resurrecting the Person*, 53–106.

<sup>106</sup> This idea comes from Thomas S. Kuhn, *The Structure of Scientific Revolutions*, 50th anniv. ed. (Chicago: University of Chicago Press, 2012).

external social systems are shaped by medical labels, a medical worldview also can shape the experience of parents. Susan Kelly, a medical sociologist at Exeter University, has pointed out that parents' experiences and understandings of impairment are "shaped by medical labels and meaning" due to "related interactions with medical and rehabilitation professionals, and . . . daily management issues."<sup>107</sup> That is, while mothers or parents interact with the major social and medical agencies, the concepts and vocabularies they are learning can permeate and shape mothers' experience and the way they interpret their experiences.

Kelly, further, argues that this is quite a common phenomenon observed in parents' experiences.<sup>108</sup> She pointed out that "a number of parents in the study were in the process of seeking a medical diagnosis to provide objective, medical confirmation of their subjective experience of impairment in their child."<sup>109</sup> She calls this an "impairment in search of a label."<sup>110</sup> Kelly argues that one reason parents may seek medical validation is because not knowing what is going on with their children can signify bad parenting to others. She further observed that for some parents, gaining the medical diagnosis "was expressed as central to the act of good parenting."<sup>111</sup> I would add another reason: that there are very few emotional or spiritual resources available to and popular for mothers as a guide or companion in the process of encountering children's disability that carefully considers a mother's spiritual and emotional status. In addition, the need for this kind of support is not recognized. Under these circumstances, medical confirmation is almost the only tool that affirms a mother's experience. According to Kelly, "without medical confirmation of organic impairment, the behavioral and

---

<sup>107</sup> Susan E. Kelly, "A Different Light: Examining Impairment through Parent Narratives of Childhood Disability," *Journal of Contemporary Ethnography* 34, no. 2 (2005): 195.

<sup>108</sup> Kelly, "A Different Light," 180–206.

<sup>109</sup> Kelly, "A Different Light," 205.

<sup>110</sup> Kelly, "A Different Light," 205.

<sup>111</sup> Kelly, "A Different Light," 205.

cognitive differences they perceive in their child are interpreted—by institutional gatekeepers to rehabilitative services and educational programs—as evidence of incompetent, immoral, or ‘bad’ parenting.”<sup>112</sup> Furthermore, once parents obtain a medical diagnosis, which provides a framework to understand their children’s behavioral and cognitive differences, they can communicate with others about it. Medical diagnosis becomes a “conceptual vehicle” through which mothers are able to translate their subjective knowledge into more accessible and communicable language.<sup>113</sup>

Karyn’s case is a prime example. (Although the theme of “impairment in search of a label” wasn’t evident in Alice’s case, in my pilot research and my previous research, this topic was one of the prominent experiences that parents encounter.) In the beginning of Karyn’s narrative, we saw that she ‘sensed’ something wrong with Corbyn. While Karyn did her best to search for the reason behind her fear, making multiple medical appointments, she also experienced “the difficulty of identifying a biological and objective source of impairment that could validate [her] experience to others.”<sup>114</sup> Early on, neither Karyn’s mother nor Corbyn’s doctors believed her. She knew something was wrong and tried to convince them, but it was only her daughter’s seizure that proved she was correct. In this case, Karyn’s subjective experience about her daughter neither agreed nor affirmed by anyone around Karyn and, to some degree, even herself. The medical diagnosis of Corbyn validated Karyn’s own internal sense that Corbyn had a serious problem. The medical paradigm enables Karyn and her family to make sense of what was going on with Corbyn. Only when a medical diagnosis was made, possible treatment plans followed. This resolved the conflicts between Karyn vs. the doctors and Karyn vs. her

---

<sup>112</sup> Kelly, “A Different Light,” 205.

<sup>113</sup> Kelly, “A Different Light,” 193.

<sup>114</sup> Kelly, “A Different Light,” 193.

mother about Corbyn's physical condition. It not only resolved the interpersonal conflicts but cleared away the doubts she had. Corbyn's behavior difference was now translated into medical language that her family and medical professionals could all agree on and accept.

Second, the process which mothers go through to search for the diagnosis can also help them to make sense of what has happened to their children and to negotiate their own acceptance of their children's impairment. The medical professionals usually function as gatekeepers in the beginning of that process. This was evident when Alice and Karyn had to face their children's disabilities. It is a medical diagnosis or medical advice that mothers seek when they face something strange about their children. These mothers searched for diagnoses and were informed about what options and paths were available to them. In most cases, the medical worldview is the very first option that is provided to mothers to understand their children's conditions. What takes place through this process is that mothers begin to learn the medical language and concepts that will help them make sense of their children's' impairments. For instance, Kelly found out that mothers "achieving clinical identification and labeling atypical development in their child involved negotiation with medical and formal care systems about the existence, nature, and extent of abnormality or impairment."<sup>115</sup> This was the case for both Alice and Karyn. Through this process, the two mothers began to negotiate to what degree they could accept their children's impairment and to what degree they could not.

The gradual and long process of seeking treatment and managing it with their children involves a process of negotiation by mothers to discern what kind of treatment they will allow their children to have. It also forces mothers to be educated, as Alice said. Although both mothers wanted 'cures' for their children—as far as that was possible—they had to follow the

---

<sup>115</sup> Kelly, "A Different Light," 198.

step-by-step treatment plan available to them. Gradually, mothers learn what is possible and what is not and make the decision when it is time to stop treatment.<sup>116</sup> This process makes it possible for mothers to organically adjust to their children's realities. From a psychological perspective, a process of negotiation is taking place.

Third, surprisingly, the medical worldview, to a large extent, aligns with mothers' emotional responses to their children's disabilities; thereby, the medical worldview functions to affirm mothers' emotions. It is difficult to discern whether the correlation of mothers' worldviews is due to the overwhelming influence of the prevalent medical worldview in the first place. What I am interested in is how this correlation functions, rather than in what causes this correlation. Clarifying the genesis of that correlation is important, but that is not the purpose of this dissertation. Rather, I seek to describe, discuss, and learn from the phenomenon as articulated by Alice and Karyn.

For mothers of children with disabilities, validation of emotion becomes an increasingly important issue because, as Alice's and Karyn's narratives reflect, unless they intentionally search for it, which they didn't, there is little emotional support available for mothers and parents. (The reason why it is important to acknowledge one's emotions will be discussed in chapter 7.) Using psychologist Marc Brackett's phrase, mothers of children with disabilities rarely have "permission to feel."<sup>117</sup> Their emotions that result from their specific context that involves experience of disability are rarely acknowledged or affirmed, which can make those emotions difficult to process. In this situation, the medical worldview operating in our society is nearest to an account of disability that aligns with and thus functions to affirm mothers'

---

<sup>116</sup> For example, today Alice's and Karyn's children are not receiving treatment.

<sup>117</sup> Marc Brackett, *Permission to Feel: Unlocking the Power of Emotions to Help Our Kids, Ourselves, and Our Society Thrive* (New York: Celadon Books, 2019).

emotions. The way the medical model of disability understands human beings largely goes hand-in-hand with mothers' major perceptions of human beings.

The language and concepts of the medical worldview reflect and validate mothers' emotions, which range from a sense of loss and sadness to feelings of joy and gratitude. Thereby, the medical worldview provides outlets to affirm mothers' emotions. As I mentioned in the previous section, the medical worldview of disability is also referred to as the 'personal tragedy' model, because it perceives disability in a fundamentally negative way.<sup>118</sup> This was evident in the cases of both Alice and Karyn. Recall the moment when Alice first faced Julius' disability through his pediatrician and the phone conversation between her and the doctor. Her action of searching in desperation for a number of therapists was driven by the belief that therapy would provide at least a way of moving through this tragedy. It is noticeable that the medical worldview is indeed one of the perspectives of disability most deeply embedded in mothers. What is clear is that mothers' emotions, the way they *feel* about their children's disabilities, align with the values implicit in the medical worldview and this reality must be acknowledged and affirmed before discerning to what degree it is theologically sound or not.

It is not only these negative emotions that are validated; mothers' joy and sense of hope to some degree, correlate with the accomplishment and progress made by medical professionals. Let's go back to the *Tampa Tribune*.<sup>119</sup> Alice, although, she doesn't seek therapy as much now as she did previously, still hopes in what can be called medical progress. Alice's hope is for the improvement of Julius' abilities. In other words, Alice's happiness or well-being to some degree hinges upon Julius' progress, when seeing the idea of hope from the perspective of Andrew Lester's understanding of hope. From this perspective, it is likely that many mothers will feel

---

<sup>118</sup> Retief and Letšosa, "Models of Disability," 3.

<sup>119</sup> Peterson, "A Mother's Love."

that their emotions are understood and accepted as long as they are within the context of the medical worldview.<sup>120</sup>

One of the challenges faced by families of children with disabilities—a challenge which has not been given enough attention—relates to their emotional responses. For instance, one of the problems is not allowing a person “permission to feel” freely and entirely when it comes to family related matter. This is problematic when it comes to a person who bears the burden of caring for a family member’s dependency, such as, in the case of mothers in my dissertation. The special status given to families and family relationships has the danger of forcing a person to claim triumph over the especially negative emotions of anger, frustration, loss, grief, and hatred. If a person represses these emotions, these repressed negative emotions are likely to lead to depression. Or, they can cause confusion when facing a negative situation.<sup>121</sup> The process of facing and raising children with disabilities can cause mothers to experience and feel emotions more extremely than generally known and as Alice mentioned, there are not enough space for parents to freely and honestly open up their experiences and emotions.

Fourth, the medical worldview offers a psycho-spiritual source of hope to mothers. In the previous section, I introduced the vision of hope inherent to the medical worldview, especially in light of Andrew Lester’s understanding of finite hope. Finite hope means a desire a person has toward finite objects. Lester draws examples, such as “our hope for a pay raise, acceptance into a certain school, a good grade, a positive word from an inquiry.”<sup>122</sup> In the context of my dissertation mothers’ hope toward their children which congruent with the medical worldview

---

<sup>120</sup> What is certain is that the medical model of disability validates mothers’ emotions of desperation and fear in response to loss and trauma.

<sup>121</sup> A person might say, for example, “I do not know what to feel.”

<sup>122</sup> Lester, *Hope in Pastoral Care*, 63.



for their children to have normal lives is understood as finite hope by Lester.<sup>123</sup> In Andrew Lester's worldview, most of the finite hope are likely to be dysfunctional, less life-giving because when it remains unaccomplished, it can easily lead a person to despair. From Lester's perspective, the future story of the medical worldview is dysfunctional, yet when we explore both Alice and Karyn's story, we can see the hope, although finite, of the medical understanding, cure, and healing becomes a significant source of drive of mothers, even to the point that Karyn said her daughter provides the meaning of her life and she will do whatever it takes to her to make Corbyn able as possible. Alice didn't explicitly say this but it is obvious from her life stories that her priority in her daily life is Julius's betterment. I agree with Lester that these finite hopes cannot be a spiritual strength in an ultimate sense; in the longer term, unless mothers found their children improving, they might easily experience desperation. However, in the short term, the medical worldview offers hopes that mothers can rely on when there is nothing else that they can hold onto—especially when they cannot help but to think within the medical worldview, even for a short span of time, until they move on the different worldviews. Although finite, the hope for cure yields a spiritual support to sustain mothers' lives at least in the short term. It was a source of "get up and go" energy for daily living. Although hope in the medical worldview may ultimately lead to despair, it can be a means, especially for mothers, to sustain their hope and a source of support in their daily lives. This indicates that the boundary between functional and dysfunctional future stories can be blurred.

A similar insight was found in Kate Bowler's *Blessed: A History of the American Prosperity Gospel*. The prosperity gospel that Bowler examines is "a wildly popular Christian message of spiritual, physical, and financial mastery that dominates not only much of the

---

<sup>123</sup> Hur, "Triumphal Narrative and Absurd Narrative," 47–62.

American religious scene but some of the largest churches around the globe.”<sup>124</sup> Bowler focuses on faith, wealth, health and victory as subjects of the American prosperity gospel. The vision of hope of the medical worldview of disability aligns with health described in Kate Bowler’s prosperity gospel. According to Bowler, the movement of the prosperity gospel fosters hope, “a power that unleashes spiritual forces and turns the spoken word into reality” that guaranteed a special form of Christian power to reach into God’s treasure trove and pull out a miracle. It represented the triumph of American optimism over the realities of a fickle economy, entrenched racism, pervasive poverty, and theological pessimism that foretold the future as dangling by a thread. Countless listeners reimagined their ability as good Christians—and good Americans—to leapfrog over any obstacles.<sup>125</sup>

The subject Bowler examines, in Lester’s perspective, mostly can offer only finite spiritual resources; however, from her ethnographic research Bowler found that these finite resources are functioning as the source of willpower for people not only to live their daily lives but also to keep their faith in God. Similarly, hope in the medical worldview, no matter its finite nature, functions to keep Alice and Karyn going.

Fifth, the medical worldview function for mothers to feel “sense of belonging, inclusion” from the larger society because no doubt it is a worldview of majority. Here I am less concerned about to what degree it is theological sound or not, or right or wrong, but as an individual especially part of minority group, it is undeniable to consider the weight of authority given to the medical worldview. The medical worldview is one of the most influential worldviews operating in the U.S. and in Alice and Karyn’s narratives. I argue that the medical worldview implies

---

<sup>124</sup> Kate Bowler, *Blessed: A History of the American Prosperity Gospel* (New York: Oxford University Press, 2018), 3.

<sup>125</sup> Bowler, *Blessed*, 7.

mothers' desires to be affirmed and recognized as members of a larger society, the medical worldview, here, functions as a currency, a means, a sort of membership card. It is possible, I argue, to interpret mothers' deeply held beliefs on the medical worldview as coming from their deep desires to be connected and related. The first five functions that we saw is mostly dealing with mothers' psycho-spiritual aspect, now I turn to more external factors such as how the medical worldview function to generate and sustain social relationship of mothers.

The medical model of disability becomes a criterion or standard by which communities' function. Communities of parents or families of children with disabilities are generally built around and organized by children's diagnoses. Medical language and its vocabularies become the main 'language' and 'source' that community members participate in and share. Alice and Karyn both talk about the communities they are involved in and say that the very existence of those communities is helpful to them. Through these communities, practical information is circulated, relationships are built and emotions— especially emotions caused by their children—are shared.

Both Alice and Karyn, when asked what has been helpful, commonly answered that they found most help from the online community of parents of children with disabilities. This was not only because they were able to find and share useful information such as what happens at different ages and which therapies are needed. These communities were also helpful because the mothers were able to share what they felt in relation to their children, feelings they were able to share in no other places.

These communities were considered the most important, and the rarest, sources of support to Alice and Karyn. In the case of Alice, she hoped to help create a space or community for parents. She said, "It would be really nice if there was a true place you could go where

parents can talk about the positive and negative things that they have done.” Research done by pastoral and practical theologians as well as psychologists constantly underlines the importance of belonging to a community. For example, psychologists demonstrate the correlation between a sense of belonging and a feeling of depression. Having a sense of belonging and sharing the belief that a person is deeply cared for generates and fosters a willingness to endure life’s challenges.

From slightly different vantage point, Patton is addressing the more fundamental need of human beings to belong. Patton points out that the reason why the experience of community is important is not because of the experience of community itself but because communities function to address the human need for connection.<sup>126</sup> What is more significant is, as Patton said, “the awareness of participating in a common task and of not being alone in the difficulties and responsibilities of life.”<sup>127</sup> This applies to both Alice and Karyn in that these mothers’ actively participate in community by planning and seeking their children’s cure. By joining this community, mothers experience “not being alone in the difficulties and responsibilities of life.”<sup>128</sup>

Lastly, I would like to raise pragmatic benefit mothers and their children with disabilities can receive that cannot be dismissed or denied. The medical model provides pragmatic benefits for mothers. For instance, mothers of children with disabilities are eligible to receive two major benefits: Supplemental Security Income (SSI) payments for children with disabilities and Social Security Disability Insurance benefits for adults disabled since childhood.<sup>129</sup> These services are

---

<sup>126</sup> Patton, *Pastoral Care in Context*, 22.

<sup>127</sup> Patton, *Pastoral Care in Context*, 23.

<sup>128</sup> Patton, *Pastoral Care in Context*, 23. Alice and Karyn are concrete examples of this.

<sup>129</sup> Social Security Administration, *Benefits for Children with Disabilities*, Pub. no. 05-10026 (Social Security Administration, January 2022), 1, <https://www.ssa.gov/pubs/EN-05-10026.pdf>.

available to those who meet the definition of disability set by the Social Security Administration,<sup>130</sup> reflecting the medical worldview of disability.

Factors such as the child's income and resources and the child's level of disability are the primary criteria for determining the Supplemental Security Income (SSI). A "child must meet all of the following requirements to be considered disabled and, therefore, medically eligible for SSI."<sup>131</sup> Those factors are:

The child, who is not blind, must not be working or earning more than \$1,310 a month in 2021. A child who is blind must not be working or earning more than \$2,190 (this earnings amount usually changes every year).<sup>132</sup>

The child must have a medical condition or a combination of conditions, that resulted in 'marked and severe functional limitations.' This means that the condition(s) must very seriously limit the child's activities.<sup>133</sup>

The child's condition(s) must have been disabling or be expected to be disabling for at least 12 months; or the condition must be expected to result in death.<sup>134</sup>

Parents need to prepare detailed information "about the child's medical condition and about how it affects the child's ability to perform daily activities."<sup>135</sup> In doing so, Social Security encourages parents to "give permission to the doctors, teachers, therapists, and other professionals who have information"<sup>136</sup> related to the child's condition to send that information. This information goes to the Disability Determination Services office of their own state that will decide whether the child meets the criteria for disability. This is only a snapshot of the Social Security program, but it is obvious that parents who hope to receive any ongoing support must prove that their child is disabled in terms of the medical worldview. In addition, once the child starts receiving SSI, the law requires the Social Security Administration to review the child's

---

<sup>130</sup> Social Security Administration, *Benefits for Children with Disabilities*, 1.

<sup>131</sup> Social Security Administration, *Benefits for Children with Disabilities*, 1.

<sup>132</sup> Social Security Administration, *Benefits for Children with Disabilities*, 2.

<sup>133</sup> Social Security Administration, *Benefits for Children with Disabilities*, 2.

<sup>134</sup> Social Security Administration, *Benefits for Children with Disabilities*, 3.

<sup>135</sup> Social Security Administration, *Benefits for Children with Disabilities*, 3.

<sup>136</sup> Social Security Administration, *Benefits for Children with Disabilities*, 3.

“medical condition from time to time to verify that his or her disability still meets” the criteria. This ranges from “at least three years for children younger than age 18 whose conditions are expected to improve or for which improvement is possible” or “by age 1 for babies who are getting SSI payments because of their low birth weight.”<sup>137</sup> The review process necessary to prove constantly that their child is still disabled may remind parents or related families of the medical way of seeing “disability.”

Practical theologians—such as Don Browning and Pamela Couture—point out that “social science is not ‘value free’”<sup>138</sup> and that certain beliefs are embedded in social science and social policies. What values or theology are embedded in the requirements of the Social Security Administration? Do these beliefs influence the mother’s experience? If so, how do they shape the mother’s theology? What these parents need to undergo in order to receive governmental support is similar to refugees who attempt to obtain asylum in the United States. According to legal scholar Jessica Mayo, in order to meet “the standard required to obtain asylum, applicants must focus on their suffering, describing themselves as victims of their persecutors and their native land.”<sup>139</sup> She asserts that this kind of victim narrative “can have long-lasting effects, primarily on the client but also on the attorney and on society as a whole.”<sup>140</sup> It results in the perception of applicants as “powerless victims, rather than as a culturally diverse group of survivors who are contributing to the changing fabric of American society.”<sup>141</sup> Parents of children with disabilities are in a different situation than refugees; they are not victims, and the parents I am referring to are legitimate citizens of the United States. However, what is common in these two groups of

---

<sup>137</sup> Social Security Administration, *Benefits for Children with Disabilities*, 5.

<sup>138</sup> Pamela Couture, “Practical Theology and Social Policy,” in Miller-McLemore, *Companion to Practical Theology*, 4.

<sup>139</sup> Jessica Mayo, “Court-Mandated Story Time: The Victim Narrative in U.S. Asylum Law,” *Washington University Law Review* 89, no. 6 (2012): 1487.

<sup>140</sup> Mayo, “Court-Mandated Story Time,” 1487.

<sup>141</sup> Mayo, “Court-Mandated Story Time,” 1487.

people is that they are in a position that requires them to constantly disclose and prove what are societally considered to be “weaknesses.” Engaging in some of the social policies, to some extent, can function to reinforce and educate people of the embedded philosophy of certain institutions. For example, in case of receiving disability benefits, a person has to understand requirement and condition to whom benefits are given. If one is in need of the benefit and fit the condition, a person likely go through the process to prove that she is eligible to receive this. In this regard, participating to certain social policies can make a person repeatedly to seek and to prove the given status of disability as part of her integral identity by filling out the form and saying the name of disability for social services and medical services. The benefits are provided only when a child is disabled, which functions to keep their dependent position within society. The actual support they receive is directly related to the medical perspective. The documentation of a child’s disability, and the financial and personal support they receive, to some degree, function to reinforce medical understanding of disability, the most prominent understanding of disability is society.

## Chapter 6

### Prospect for Developing Mothers' Practical Wisdom as Normative Virtue: Normative Task

In the previous chapter, I explored mothers' living webs of worldviews. A variety of worldviews can be orchestrated in mothers' lived theologies making connections with different communities, helping them make sense of their children's disabilities and offering ways to navigate and negotiate mothers' hopes and dreams with the embodied realities their children face. Now, the question becomes *how* is it possible for mothers to have this capacity to hold different worldviews when those worldviews are seemingly, and sometimes theoretically, irreconcilable?

I propose that this ability of such mothers has great potential to be conceptualized as practical wisdom that possesses significant normative value. Discerning normative value is called normative task in Osmer's practical theological project.<sup>1</sup> The normative task involves discussion of "using theological concepts to interpret particular episodes, situations, or contexts, constructing ethical norms to guide our responses, and learning from 'good practice'."<sup>2</sup> Utilizing this normative task, Osmer attempts to answer "What ought to be going on?"<sup>3</sup> and this chapter is my effort to answer that question, especially from a pastoral theological perspective and an ethical perspective.

The goal of this chapter is to unpack what I see as mothers' practical wisdom. I argue that the phenomenon of mothers' practical wisdom that I elicit from mothers' lived theology can

---

<sup>1</sup> Osmer, *Practical Theology*, 4.

<sup>2</sup> Osmer, *Practical Theology*, 4.

<sup>3</sup> Osmer, *Practical Theology*, 4.



result in a beneficial practice that is able to assist and sustain mothers from both a communal and psychosocial perspective. Then, I explore how this quality of mothers can be understood within the care ethics tradition. Mothers' practical wisdom can serve as a great communal and psychospiritual resource which has significant potential to be considered as form of care ethics at the same time that mothers' practical wisdom challenges the care ethics to provide further articulation. In this regard, when examining mothers' practical wisdom from care ethics perspective, it becomes preliminary research to explore the possibility of whether mothers' practical wisdom can be adequate care ethics from the care ethics perspective.

Osmer points out that, while the normative task would help to determine what ought to be encouraged, it would not tell how to accomplish it.<sup>4</sup> How practical wisdom, the normative practice, can be accomplished will be offered in the next chapter. With this in mind, this chapter will describe what I understand as mothers' practical wisdom and explore it from the ethic of care perspective and as a psycho-spiritual resource. Now, let's look at the definition of mothers' practical wisdom.

### **Mothers' Practical Wisdom**

I define mothers' practical wisdom as an ability that enables mothers to negotiate different worldviews and sustain a living web of worldviews by holding and making use of compatible and incompatible worldviews simultaneously.

What I saw from Alice and Karyn was mothers' practical wisdom as a phenomenon not necessarily intentional nor a result of conscious action. However—as I will soon convey—although this wisdom might be unintended, I see it emerging as a result of the experiential

---

<sup>4</sup> Osmer, *Practical Theology*, 131–32.

wisdom that mothers embody. In this section, I propose to develop this practice as both care ethics and psycho-spiritual resources. While doing so, mothers' practical wisdom becomes a living site for interdisciplinary studies of pastoral theology and care ethics—both of which fields cross paths that enable us to elucidate the main characters of mothers' practical wisdom.

I now begin to explore the benefits of mothers' practical wisdom. I will begin to explore from the outside and move toward exploring mothers' inner world. Mothers' practical wisdom can positively influence their social connections and lead to psychological sources that one to process experiences of ambivalence that occur from the various meanings of disability.

### **Mothers' Practical Wisdom as a Communal Resource**

First, practical wisdom, by providing mothers the ability to hold different ideas about disability, enables mothers to foster various social relationships and connections. Mothers' practical wisdom, by virtue of its ability to overlap worldviews and create connections, allows mothers to network with a wide breadth of communities and individuals by sharing worldviews. The complex webs of worldviews can function to connect and disconnect people around different understandings of disability. In sharing our worldviews, we learn about the views of others, share our own, and in the end, build bonds with those with whom we have already built rapport or diverge from others. From this relational perspective, different worldviews of disability (can) carry different weights, depending on the individuals involved. And ironically, the medical worldview of disability can be considered as more powerful as it yields more possibilities to promote social and personal relationships for these mothers—a positive quality unacknowledged by disability theological literature.

Karyn's "living web of worldviews," for example, illustrates how accessing diverse worldviews can provide a mother with access to multiple social and spiritual resources, and vice versa. Sharing worldviews or not can influence social and family relationships and connections. When people diverge in worldviews of disability, it can create interpersonal conflicts even within a family, resulting in the severance of meaningful familial ties. Karyn shared how her relationship with her sister fell apart after her daughter was born. Upon hearing her sister use pejorative language to describe Corbyn within a narrow medical worldview, Karyn could no longer reconcile with her sister. This divergence in thought and disability worldviews was one that resulted in emotional cut-off. Karyn and Alice often experience transformations or the emergences of new worldviews after caring for their children with disabilities, which, in turn, can result in friction with other family members.

A prime example of a new social relationship Karyn was able to build is the connection she found with her daughter's therapist. Although the therapist's role was to support her daughter, Karyn found that this therapist presented qualities as well as a passion and dedication to care that Karyn had never witnessed before. This encounter with Corbyn's therapist was one that she could not fully put into words, with gratitude at the heart of their bond. Compared to other healthcare providers, her daughter's therapist allowed Karyn to realize herself in ways she could not before. Their connection was so meaningful that she felt the overwhelming desire to become a speech therapist herself. In the process of self-realization, Karyn found that she and Corbyn's therapist shared the same worldview of disability as well as goals to alleviate Corbyn's struggles with her disability.

More specifically, there are three benefits mothers, such as Alice and Karyn, experience from forming and maintaining social relationships. First, mothers can gain practical wisdom

about parenting their children and understanding their children, understanding disability, and learning how to navigate these difficult topics. Mothers come from a place of ‘not-knowing’ about disability, and, through creating and fostering social relationships, they gradually move along to the place of ‘knowing.’ As we saw from both Alice and Karyn, emotionally, it is nearly a traumatic experience to face the disability of one’s child. A new mother with a child with a disability can fear, like any other mother, to fail as a mother, caregiver, and support system. She becomes desperate to learn and, what I am calling the pastoral encounter, brings forth educational opportunities.

Frightened new moms often seek counsel from older, more experienced mothers, as we saw with Alice. Alice had an opportunity to connect with another mother whose son has a similar condition as her son. Seeking out connections with others can help mothers in obtaining information that they may find helpful in caring for their children. Moreover, a community itself can function as a forum where mothers seek advice, exchange valuable information, develop relationships, and find mentors. Both Alice and Karyn referred to their use of social media, including Facebook groups such as CHASA as a primary resource for coping with their children’s disabilities. They shared knowledge on schooling, education, and cures; activities that their children can engage in; and develop(ed) friendships with other mothers. Social media platforms can also become a place where they exchange particulars about pragmatic support such as finance, Social Security support, and how to navigate troubles with agencies and bureaucracies.

Second, mothers receive moral support by sharing, and often commiserating over, the parenting experience together. Neither Alice nor Karyn intentionally sought emotional support for themselves. Rather, community support and interaction, including ‘weak-ties’ relationships

and casual interactions with medical professionals, including therapists, became instrumental sources of moral support, even to the point where Karyn decided to be a therapist herself. These interactions help mothers share the burden of motherhood with similarly minded people.

Through these pastoral encounters, the experiences of motherhood can be shared as parents are given the space and ability to share their struggles and pains with a community.

The communal effect of the first and second elements contribute to a third: empowering mothers' sense of agency. This can be explained by the psychological concept of "in-group favoritism." Ingroup favoritism refers to "the tendency to favor members of one's own group over those in other group,"<sup>5</sup> including oneself. That is a person is more likely to favor group members' ideas over their own. This psychological phenomenon is well-documented, but its mechanisms are unclear.<sup>6</sup> Among the many functions of in-group favoritism is the increase of self-esteem. That is, "identification with one's group motivates individuals to distinguish their group from others to attain and preserve positive collective self-esteem as a group member."<sup>7</sup> When a person is a part of an in-group, the influence of polarization is rooted in their mind and creates a sense of 'we' versus 'them' or 'others.' This makes people conceive that 'we' are better or different from the 'other.' This bond created in-group offer a safe space that comes as a privilege of being a part of an in-group that can (but not always) lead to a feeling of empowerment.

As a result, a sense of agency is strengthened as the individual gains emotional support that use as a willpower of its own.<sup>8</sup> When considering a mother's social context, these benefits

---

<sup>5</sup> Jim A. C. Everett, Nadira S. Faber, and Molly Crockett, "Preferences and Beliefs in Ingroup Favoritism," *Frontiers in Behavioral Neuroscience* 9, no. 15 (February 13, 2015), <https://doi.org/10.3389/fnbeh.2015.00015>. I thank Ale Estrada for pointing me to this concept of ingroup favoritism.

<sup>6</sup> Everett, Faber, and Crockett, "Preferences and Beliefs."

<sup>7</sup> Everett, Faber, and Crockett, "Preferences and Beliefs."

<sup>8</sup> Everett, Faber, and Crockett, "Preferences and Beliefs."

from communal support bear more weight. Through this type of encounter with others, through experiencing inclusiveness, mothers experience mothers' way of experiencing liberation.<sup>9</sup>

In addition, the intentional and conscious act of employing different worldviews of disability encourages the development and support of a sense of agency. Earlier, I delineated the phenomenon of mother's utilizing mother's practical wisdom in their use of different worldviews and asserted that this practice can be a form of intentional pastoral care. As a pastoral care practice, mothers' practical wisdom can strengthen their sense of agency because the process—of making judgments, discerning the pros and cons of each worldview, and exercising choices—requires agency and autonomy to oversee and actualize the process.

### **Mothers' Practical Wisdom as a Psycho-Spiritual Resource**

Second, practical wisdom allows mothers to hold psychological experience of ambivalence for understanding disability. Broadly speaking, mothers of children with disabilities most likely face two kinds of ambivalence. First is the ambivalence that is experienced by a mother toward her children. This type of ambivalence is found among mothers in general. Second is the ambivalence about the meaning of disability. Once mothers become aware of their children's disability, they are exposed to a number of different meanings of disability. Being exposed to the differences can cause feelings of ambivalence. Mothers' practical wisdom especially is helpful for mothers with this second kind of ambivalence.

---

<sup>9</sup> See Graham, *Transforming Practice*, 183–86, on women's sense of autonomy, empowerment, and relationship.

In order to understand the psychological phenomenon of ambivalence we need to begin with the process of evaluation. Human cognition and perception are evaluative in nature.<sup>10</sup> One of the important functions of evaluation is “preparing and guiding our behavior”<sup>11</sup> by which people set their attitude. Evaluation can take place easily and that leads to making a decision on attitude, when it is determined that the association is either positive or negative.<sup>12</sup> However, there are moments where coexistence of positive and negative associations can be present in one attitude. And this is called ambivalence. Ambivalence means “a psychological conflict between opposing evaluations, often experienced as being torn between alternatives.”<sup>13</sup> There are two major characteristics that construct the psychological phenomenon of ambivalence. Those are “first, both positive and negative associations need to be present. Second, these associations can be (but not always are) relevant at the same time.”<sup>14</sup> This is exactly the case for mothers of children with disabilities. A variety of worldviews of disability both have positive and negative associations and those are available for mothers to adopt at any time.

According to Frank van Harreveld, studies have commonly shown that the experience of ambivalence engenders negative feelings and discomfort. He states: “ambivalence leads to negative affect and this affective response is the fuel that drives subsequent effects of ambivalence on cognition and behavior.”<sup>15</sup> In response to this, people choose one of the

---

<sup>10</sup> Frank van Harreveld, Hannah U. Nohlen, and Iris K. Schneider, “The ABC of Ambivalence: Affective, Behavioral, and Cognitive Consequences of Attitudinal Conflict,” *Advances in Experimental Social Psychology* 52 (2015): 286, <https://doi.org/10.1016/bs.aesp.2015.01.002>.

<sup>11</sup> G. W. Allport, “Attitudes,” in *Handbook of Social Psychology*, ed. C. Murchison (Worcester, MA: Clark University Press, 1935), quoted in van Harreveld, Nohlen, and Schneider, “The ABC of Ambivalence,” 286.

<sup>12</sup> van Harreveld, Nohlen, and Schneider, “The ABC of Ambivalence,” 286.

<sup>13</sup> Iris K. Schneider et al., “The Path of Ambivalence: Tracing the Pull of Opposing Evaluations Using Mouse Trajectories,” *Frontiers in Psychology* 17 (2015), <https://www.frontiersin.org/articles/10.3389/fpsyg.2015.00996/full>.

<sup>14</sup> van Harreveld, Nohlen, and Schneider, “The ABC of Ambivalence,” 288.

<sup>15</sup> van Harreveld, Nohlen, and Schneider, “The ABC of Ambivalence,” 285–86.

following patterns of delay in making a final decision. In other words, they use choice delay (procrastination), compensatory cognition, systematic processing or heuristic processing.<sup>16</sup>

It is difficult to pinpoint exactly from among the above what pattern of activities mothers are engaging with. It appears to me mothers' practical wisdom is developed throughout a long period of time. It could be a little bit of everything. I think it is possible to see that this is a result of mothers' delay in making a decision being caused by their having a fixed understanding of disability. There are many contributing reasons for this.

- A. Ambivalence attitude holders are easily persuaded by the majority argument. That would be the medical understanding for the case of these mothers.
- B. It could be the case that they are 'delaying' their decision as to what to think about disability.

This delay can have similar attributes with the procrastination: fear of confronting reality. However, there is another important and inevitable reality that could influence mothers not to help but to delay. That is, that mothers are still in the process of working on their children's disability from the medical perspective. In this worldview, their children's disability has the potential to lessen or to be removed. This fluidity is one of the inevitable factors that hinders them from settling on their understanding of their children's disability, the process of going through the time needed to figure out the meaning of disability. They try to envision their children as independent as possible. They see their children from the medical perspective which inevitably makes mothers delay deciding which definition they will adhere to.

From what I observed, mothers do not seem to be aware that they were in the midst of this ambivalent experience or that they are holding on to different understandings of disability.

---

<sup>16</sup> van Harreveld, Nohlen, and Schneider, "The ABC of Ambivalence," 285–86.



Likewise, I wasn't able to find any visible sign of distress that directly resulted from the ambivalent meaning of disability. The fact that it wasn't discovered in my research does not mean it does not exist. This will be one subject for further research. At least, for now, and for this reason, I cannot argue that the systematic effort that I am putting forth to conceptualize the notion of practical wisdom is to lessen the existing distress; rather it may be more for the purpose of preventing potential discomfort given the result of psychological studies that in general the experience of ambivalence causes discomfort. However, what I can clearly argue is that there is no theologically or psycho-spiritually or ethically corresponding idea that affirms this reality and the very real experiences of mothers' lived theology. And because of the value that I see in affirming that reality, I would like to explore the prospect to promote it as a normative value.

Whether it is the process of delaying the systematic or heuristic process, the process itself is real and mothers do engage in it and that process necessarily entails psychological and pragmatic benefits for them. For this reason, I am trying to put effort into conceptualizing it, which I see as part of "systematic processing" in order to lessen the experience of conflict and any potential discomfort.

Practical wisdom that they already have has helped them to navigate and cope with the experience of ambivalence. Mother's practical wisdom—by allowing and supporting the living web of worldviews—gives them psychological freedom in understanding disability. The framework of a living web of worldviews does, to some degree, neutralize the value of each worldview. Each worldview is valued differently according to the context in which they are considered. For example, theological worldviews are the most valued understanding of disability within the theological or church setting, while the medical or legal worldviews hold the most

political power in society. The living web of worldviews and practical wisdom value each other equally by considering the great variety of contexts and their accompanying inevitable value system that exist in our reality. This equal consideration of each of the worldviews helps mothers to avoid feeling any sense of guilt and allows them to freely explore and choose worldviews of disability that meet the needs of each specific situation.

### **Prospects for Developing Mothers' Practical Wisdom as an Ethics of Care<sup>17</sup>**

I argue that in order for mothers' practical wisdom to be considered as an ethics of care several notable characteristics of mothers' practical wisdom have the potential to be considered as part of a care ethics. However, several points remain that must be addressed.

Let me explain what care ethics paradigm is. The care ethics paradigm provides meaningful and humanistic insights into an understanding of mothers' practical wisdom. Let me briefly explain the care ethics paradigm. The ethics of care is one of the normative moral theories and is an approach to moral theorization.<sup>18</sup> Care ethics, has grown between the cracks of justice-oriented understandings of morality such as Kantian moral theory, utilitarianism, and virtue ethics<sup>19</sup> as a necessary way to resist their shortcomings and oversights. These traditional ethical normative theories focus primarily on how just the person or government is or to what degree a person's disposition is justice-oriented. From this perspective, women were considered 'less just' than men because what have been traditionally and broadly considered womanly concerns—matters that involve caring and nurturing—have not been regarded as possessing any moral value. For this reason, the care ethics tradition has attempted to recognize those unnoticed

---

<sup>17</sup> This work is modeled after Grace Y. Kao's "Prospects for Developing Asian American Christian Ethics," *Society of Asian North American Christian Studies* 3 (2011): 91–102

<sup>18</sup> See Held, *The Ethics of Care*, 3.

<sup>19</sup> Held, *The Ethics of Care*, 3–4,

aspects on caring, nurturing and relationship that were not deemed important in other, more established, ethical theories. Those concerns are relational realities women experience in the context of moral issues.<sup>20</sup>

As a result of maintaining this different emphasis, the care ethics tradition has the capacity to understand mothers' practical wisdom described above. As I mentioned in Chapter 3, the field of disability theology tends to follow the trajectory of traditional ethical theories. In particular, it focuses on justice by highlighting the normative: What is the right theological understanding of disability and how should a community function and flourish, based on its theological understanding of disability? While searching for the theologically "right" and "sound" meaning of disability, what is overlooked is why some people—in the case of my dissertation, mothers of children with disabilities—cannot help but adhere to the theologically less right and sought perspective on disability, such as the medical worldviews. This theological trend has unexpected ramifications especially in caring contexts. It inevitably results in an inadequate affirmation and understanding of mothers' lived theology. The care ethics tradition, however, by focusing instead on relationships, experiences, and gender sensitivity, can complement this trend of theology and can explain mothers' lived theology that current theological studies miss entirely or fail to address.

There are four important qualities that exemplify care ethics: experience, relationship, reason and whether it serves both the mother and a child. In the following section, I will describe that while care ethics' aspects of experience and relationship can fully explain mothers' practical wisdom, last two elements of reason and whether it serves both the mother and child needs further consideration.

---

<sup>20</sup> Held, *The Ethics of Care*, 4.

First, one of the distinctive attributes of care ethics is its focus on *experience* in exploring care ethics. Virginia Held, a “feminist philosopher whose work on the ethics of care sparked significant research into the ethical dimensions of providing care for others,”<sup>21</sup> goes on to describe “feminist [or care] ethics as committed to actual experience, with an emphasis on reason and emotion, literal rather than hypothetical persons, embodiment, actual dialogue, and contextual, lived methodologies.”<sup>22</sup> In the discipline of care ethics, claims of universal norms are considered “dubious” and thus mandate that scholars engage in reconsideration of abstract norms by carefully examining the phenomenon of ‘actual experience’ and its reflection, especially in regards to a mother’s experience. Simply put, the discipline seeks to theorize from the true, lived experience of mothering.<sup>23</sup> It strives to see “the most basic and most comprehensive values”<sup>24</sup> of what care means in the context of being a mother—the highs and lows, from the joys to the heartaches. Mothers’ practical wisdom indeed derives from mothers’ lived experiences as we saw from the narrative of Alice and Karyn. It is not something they could have possibly learned from a book or from another secondary source, but only from first-hand, tangible experiences

Second, then, among numerous kinds of motherly experiences, in what kinds of experiences does the care ethics tradition take interest? Care ethics is particularly concerned with exploring *the relationship* between mother and child when care takes place. It is the ‘relational’ quality that ethicists are interested in when they explore real experiences; —such as the ‘relational’ experiences of care. For example, Virginia Held, in *Feminist Morality* (1993), emphasizes that—because of the unique qualities of the relational aspects of care ethics—these relational aspects themselves are capable of critiquing conventional, male-oriented, and justice-

---

<sup>21</sup> Wikipedia, s.v. “Virginia Held,” September 2022, [https://en.wikipedia.org/wiki/Virginia\\_Held](https://en.wikipedia.org/wiki/Virginia_Held).

<sup>22</sup> Maureen Sander-Staudt, “Care Ethics,” *Encyclopedia of Philosophy*, <https://iep.utm.edu/care-eth/>.

<sup>23</sup> Sander-Staudt, “Care Ethics.”

<sup>24</sup> Held, *The Ethics of Care*, 3.

focused ethical theories and thus providing a new paradigm.<sup>25</sup> Justice-oriented ethical theories presumed human beings to be more rational and less concerned about emotion. However, Held goes further to explain that “being cared for” is a fundamental character and ontological truth of being human because a person’s need for care is non-contractual; it is a fundamental human need and “the most basic moral value.”<sup>26</sup> By pointing out the non-contractual nature of the care of mothers, Held was also able to critique the transactional, contract-oriented social relationship.<sup>27</sup> The care of mothers, proposed by Held, can be a new kind of ethical paradigm that has the transformative power to be a vision of social relationships, culture, society, and even politics that prioritizes “the flourishing of children and the creation of the human relationship.”<sup>28</sup> Sara Ruddick also perceives care ethics as something that derives from the human experience of relationships. Ruddick sees that care ethics has emerged from maternal practices to provide care and protection to children. As such, mother’s practical wisdom, that we saw from Alice and Karyn, is naturally born out of the experience of being mothers and providing care for children with disabilities, specifically, it is born from the ‘*relational experience*’ of mothers offering care.

The third element regards the consciences of those who practice care. While care ethics stems from the experience of caring, it is not simply an unconscious or totally emotional “practice.” Rather, it is a ‘rationality of care’—using Sara Ruddick’s notion which she presents in “On ‘Maternal Thinking.’”<sup>29</sup> It is born out of mothers who bear, Ruddick explains, “a disproportionate responsibility for the labor required by people who are ill, illiterate, frail,

---

<sup>25</sup> Held (1987), 38–42, quoted in Hee-kang Kim and Munsun Kang, “A Public Ethic of Care: Eva Kittay and the ‘Care Aid Program to Families with Disabled Children’ in South Korea,” *Korean Political Science Review* 44, no. 4 (2010): 12.

<sup>26</sup> Virginia Held, *Feminist Morality: Transforming Culture, Society, and Politics*, 2<sup>nd</sup> ed. (Chicago: University of Chicago Press, 1993).

<sup>27</sup> Kim and Kang, “A Public Ethic of Care,” 54.

<sup>28</sup> Sander-Staudt, “Care Ethics.”

<sup>29</sup> Sara Ruddick “On ‘Maternal Thinking,’” *Women's Studies Quarterly* 37, nos. 3/4 (2009): 305–8.

despairing, very young or very old—who are, in sum, in need of care.”<sup>30</sup> In doing so, Ruddick proposes that mothers garner specific ways of thinking and acting that require “distinctive cognitive capacities, metaphysical attitudes, and conceptions of virtue.”<sup>31</sup> Specifically by act of reason, Ruddick means the attentive love mothers exude in raising and training their children.<sup>32</sup> Ruddick describes,

Maternal thinking is a discipline in attentive love. Clear-sighted attachment, loving clear-sightedness, is the aim, guiding principle, and corrective of maternal thinking. However, neither attentive love nor any other cognitive capacity or virtue sufficiently epitomizes maternal work. Mothers learn to wait, but maternal waiting occurs in the context of action. The love of a child, in all its fullness, could not consist solely of being able to ask, say, or hear. To love a child is to do whatever is required to keep her safe and help her grow. Maternal attention is prompted by the responsibility to act and, when it is most successful, gives way to the action it informs.<sup>33</sup>

When Ruddick explains this notion of attentive love, she puts forth the opposite notion of fantasy by referencing Simone Weil and Iris Murdoch who later developed Simone Weil’s notion of attentive love. Fantasy is the opposite of attentive love because fantasy means “proliferation of blinding self-centered aims and images.”<sup>34</sup> Fantasy serves the need of one’s self and prevents one from being attentive to what is going on in the reality of another. This is similar to Margaret Farley’s understanding of love when she asserts that the relationship between two people must begin with their correct understanding of reality.<sup>35</sup> This attentiveness requires one’s conscience and intentional focus. This aspect of care ethics, I think, suits the character of mothers’ practical wisdom, especially when considering the fact that the execution of different worldviews of disability serves some kinds of need of children or mothers that require them to

---

<sup>30</sup> Ruddick, “On ‘Maternal Thinking,’” 305–7.

<sup>31</sup> Ruddick, “On ‘Maternal Thinking,’” 305.

<sup>32</sup> Sara Ruddick, *Maternal Thinking: Toward a Politics of Peace* (Boston: Beacon Press, 1995), 103–23.

<sup>33</sup> Ruddick, *Maternal Thinking*, 103–23.

<sup>34</sup> Ruddick, *Maternal Thinking*, 120n13.

<sup>35</sup> Margaret A. Farley, *Just Love: A Framework for Christian Sexual Ethics* (New York: Continuum International Publishing Group), 209–11.

sustain their work of caring. Practical wisdom is a wisdom that involves an unintentional yet cognitive decision embodied as a *reliable practice*, not merely an unconscious practice.

When it comes to mothers' practical wisdom, I must say that it is difficult to confidently say that it's a conscious act, the action that is done with intention or not. This will be yet another subject for further study. However, what I can say for now is that even though the cause of the action whether its conscious or intentional is not clear, the action embodies value and wisdom. And in this perspective, it can be close to say that the action of mothers, which is practical wisdom, could embody significant wisdom. Furthermore, mothers' practical wisdom enables such mothers to provide attentive love used by Sara Ruddick. Through their practical wisdom, mothers can gather more resources for their children while they wield various worldviews simultaneously. By not eliminating any options or restricting their capacity to accumulate worldviews, they are able to ascertain and discern between them with greater ease. For example, they can receive medical and social security support from utilizing the medical understanding of disability, while also engaging in the limited understanding that provides emotional resources needed to *be* with their children as they are. Mothers' practical wisdom is a response to their hope to provide for their children as best they can.

Lastly, let me explore mothers' practical wisdom from the last element — whether this action seeks to care for the care giver and care seeker *at the same time*. According to Carol Gilligan, feminist ethicist and psychologist, especially for women, being able to care for oneself and care for others at the same time evidences the highest level of the morality of women. Mothers' practical wisdom has a potential to be interpreted as a sign of Gilligan's highest stage of moral development as it sustains many different relationships through engaging diverse worldviews that not only enable care for their children, but also *for themselves*. However, there is

an area that Gilligan didn't anticipate. From the narrative of Alice and Karyn, we see that the separation that takes place within the relationship between mothers and children without disabilities is not addressed. Rather, there are episodes that describe and evidence mothers' inevitable way of conceiving of their children and their relationship. That is, such mothers show a definite tendency to conceive of their children as part of themselves. This complicates and challenges Gilligan's frame. From Gilligan's perspective, this is considered as Gilligan's framework which does not account for this and the closest connection is at the preconventional level where the needs of others are fulfilled first. From this perspective, mothers' sense of morality—their actions related to caring for their children—are most likely rendered immature.

Gilligan, in her book, *In a Different Voice*, proposes that women's sense of morality is different from that of men and argues that women's decisions as well as their consciousness of morality take relationships into consideration. Specifically, Gilligan acts as a proponent of this theory to oppose Lawrence Kohlberg's theory of moral development. According to Kohlberg, moral development consists of three steps: first, there is the Preconventional Level, where the needs of the self are prioritized; second, there is the Conventional Level, where a person comes to understand the notion of being a moral member of society; third, and lastly, is the Postconventional Level, where the individual pursues a universal idea of justice.<sup>36</sup> Gilligan critiques this framework because—from this point of view—a man's sense of morality is evaluated as being higher than a woman's. Gilligan argues that the development of women's sense of morality has followed a different trajectory, and Kohlberg's framework fails to account for this. That is, while men prioritize 'ethics of justice,' women, prioritize 'ethics of care.' As

---

<sup>36</sup> Lawrence Kohlberg, "The Development of Children's Orientations toward a Moral Order: 1. Sequence in the Development of Moral Thought," *Human Development* 51 (2008): 8–20.



such, Gilligan proposes a women's way of moral development that has three stages. In the first stage, Preconventional Morality, a woman focuses on herself and her need to survive. In the second stage, Conventional Morality, a woman begins to become aware of herself as a member of society and shows a tendency to help and protect others. Unlike men, the concern for the wellbeing of others often overrides her own concern for herself, which can easily result in self-sacrifice or in deeply rooted conflicts between her own needs and those of others. This tension can lead women to the last stage, Postconventional Morality. When the tensions of Conventional Morality cause women to genuinely reflect on, assess, and choose their own desire over taking responsibility for others, women may adopt the principle they kept in Postconventional Morality—to prioritize taking care of people around her. It is at this point, then, that the need of self becomes just as significant as the needs of others. Hence, at this stage, women do not (feel the obligation to?) engage in exploitative self-sacrifice. What is of note is that some women may not reach this last stage but may remain in the second stage, as Gilligan points out. This assertion begs the question: What causes this divergence?

According to Gilligan, what enables and motivates women to achieve higher levels of development are cognitive ability and the experience of changes in women's sense of self.<sup>37</sup> From Gilligan's theory of moral development, we can see that women's sense of self intimately involves and hinges on the extent of their care for others. It is when women are finally able to strike a balance between attending to their own needs and the needs of others that they reach the highest level of moral development. The way I understand Gilligan's theory of moral development is that, while not entirely following essentialization, we see that human beings can have different orientations of morality. That is, not only women can follow the model of

---

<sup>37</sup> Cynthia Vinney, "The Carol Gilligan Theory and Woman's Sense of Self," Very Well Mind, August 30, 2021, <https://www.verywellmind.com/the-carol-gilligan-theory-and-a-woman-s-sense-of-self-5198408#citation-2>.

relationship-oriented moral development, but some men also have the capacity to do so. The model is not strictly distinguished by biological sex but can depend on individual tendency, gender and learning.

From a slightly different vantage point, feminist care ethicists have also pointed out the importance of a caregiver's self-care while engaging in the care of others.<sup>38</sup> Sara Ruddick made a similar point. In order for mothers to be capable of caring for others, Ruddick asserts, they require the virtues of humility and cheerfulness. This notion is further supported by how Ruddick denotes the activity of care as "Love's labor." Hee-kang Kim and Munsun Kang, political scientists in South Korea, in their article, point out the correlation between the condition of caregiver and the care itself. They postulate that the more resources mothers have access to, to care for themselves, the better the quality of the care they are able to provide to others.<sup>39</sup> These scholars assert the consistent importance of the well-being of caregivers – a value which mothers of children with disabilities seldom uphold.

Mothers' practical wisdom enables mothers to care for themselves and their children at the same time. Mothers' practical wisdom, as we explored in Alice and Karyn's narratives, enables mothers to care for themselves as well as their children. This is because it reconciles a mother's original understanding of disability, before having their children, and what they learn from parenting their children by allowing the flexibility to hold different ideas of disability concurrently. Prior to having their children, Alice and Karyn's dominant understanding of disability was, indeed, the medical perspective. Mothers do not and need not question this assumption until they have had their children with disabilities, and what they process after having their children is mostly novel and unfamiliar. Even though the process of raising their

---

<sup>38</sup> Kim and Kang, "A Public Ethic of Care," 60.

<sup>39</sup> Kim and Kang, "A Public Ethic of Care," 60.

children with disabilities opened the door toward various understandings of disability, the medical understanding of disability is what most mothers grow up with. Even unconsciously or inadvertently, it is usually one of the fundamental ideas they rely on. This is one of the reasons why I think it must have been particularly challenging for mothers to steer away from—and later abandon—the medical understanding all together, and be willing to accept new ones. This was difficult for Alice, who had grown up with a sister with Down syndrome before having her son with disability, and even more so for Karyn, who had almost no prior experience with disability before facing that of her child. Considering this context, being flexible enough to interact with different worldviews – albeit difficult - provides points of connection for mothers to make sense of the lives they have lived so far and the lives their children are experiencing. The practical wisdom serves not only their children, but these mothers as well by enabling Alice and Karyn to accumulate the necessary experiences to strike this balance by holding onto different worldviews.

There is another point where the experience of Alice and Karyn challenge the notion of maternal activity and demand further articulation of care ethics, if these mothers' practical wisdom be adequately considered as care ethics. The meaning of care that was to arise from mothers' experiences with non-disabled children is indeed drastically different from anything Alice and Karyn might think of and experience as care. By that I mean 'motherly care' described in care ethics guidelines can have quality a quality that is different from the 'motherly care provided to children with disabilities.' When Sara Ruddick conceptualized the maternal practice of care, she described it as attending to children's demands that are specifically related to their preservation, growth and social acceptance.<sup>40</sup> These "constitute maternal work."<sup>41</sup> In her words,

---

<sup>40</sup> Ruddick, *Maternal Thinking*, 17.

<sup>41</sup> Ruddick, *Maternal Thinking*, 17.

“to be a mother is to be committed to meeting these demands by works of preservative love, nurturance, and training.”<sup>42</sup> What we have seen from the narrative of Alice and Karyn was far more than this. Depending on the states of their children’s disability, unlike the majority of mothers who can send off their independent kids, the care provided by these mothers can continue indefinitely as their children live with their disabilities. More specifically, as mothers of children with disabilities there is an obvious limit to work that can be done by mothers on their children’s social acceptance unless they become a social activist in some ways. Alice and Karyn both undertake the role of social activist within their own capacity, Alice as an artist and art teacher created a studio for children with disabilities and non-disabled children together. And Karyn not only advocates for her daughter to protect her right to have enough time for the test and also as an occupational therapist she supports and advocates for people with disabilities. However, these works hardly guarantee the social acceptance they hope for their children.

Furthermore, when these values are applied to such mothers, it can create conflicts. From Ruddick’s work, we learn that two insights are particularly relevant to such mothers. First, because children’ growth and preservation is the priority, mothers readily show tendencies to guide their children toward the most socially acceptable ways that means mothers are easily and likely gear toward the medical worldview as that is considered as one of the most prevalent understanding. Ruddick made a point that is pertinent to the experiences of mothers of children with disabilities. She said,

The more personally invested a mother is in her children’s acceptable behavior, and therefore the more rewards she expects from her maternal work, the more angry and ashamed she will be when her influence does not have the desirable effects.<sup>43</sup>

This explains the frustration, anger and shame such mothers experience.

---

<sup>42</sup> Ruddick, *Maternal Thinking*, 17.

<sup>43</sup> Ruddick, *Maternal Thinking*, 106.

From a different vantage point, Winnicott asserts that developmentally beginning with when the baby is born to year 3, the baby needs to experience unconditional love and acceptance from mothers that later consists of the important character of a child. Because of the attached notion their mothers have, not every mother is ready for the unconditional acceptance of their children.<sup>44</sup> As seen from Alice and Karyn's experience, they try to improve the physical health of their children and although this may not be considered as 'unconditional love or acceptance' from Winnicott's perspective, it is still their way of showing love from mothers' perspective. Mothers' care for their abled children goes far beyond the care of mothers with nondisabled children. When this happens—mothers playing both roles—basic motherly care and the care that can be done by a professional—the relationship between children and mothers can be negatively influenced because children to lose a chance to experience unconditional acceptance from their mothers. This is what happened to Karyn.

In this chapter, I argue the communal and psychosocial benefits of mothers' practical wisdom it brings to mothers. I also describe the prospective of mothers' practical wisdom to be considered as care ethics. While some of the qualities of care ethics adequately explain mothers' practical wisdom, there are some points that need further articulation. In this regard, I cannot argue that mothers' practical wisdom is care ethics, but I can argue that it has potential if the points I discussed above are further examined. Then, now the question becomes how we can promote mothers' practical wisdom. For this, I turn to the next section, Chapter 7, Constructive Proposal.

---

<sup>44</sup> Other resources show that the mother's conception of disability strongly influences how her child comes to conceive of his/her disability.

## **Chapter 7**

### **Shaping My Own Meaning of Disability through “Re-Membering” the Worldviews: A Constructive Proposal**

In chapter 5, I use the notion of community of worldviews to show how mothers build relationships with certain worldviews. In chapter 6, I offer the perspective of mothers’ practical wisdom. This “living web of worldviews” supports mothers and allows them to gain benefits from each worldview community; the result can be helpful as it provides care ethics and psycho-spiritual resources. Through these chapters we are able to recognize and identify mothers’ practical wisdom and the “living web of worldviews.” Based on the analysis of previous chapters, this chapter offers a way to discover, nourish and amplify mothers’ practical wisdom and their living web of worldviews. a transferable constructive proposal. To that end, this chapter, that I specifically designed for mothers of children with disabilities, delineates a narrative therapeutic approach that can be used to provide professional care givers with effective spiritual care. Its detailed guidelines consist of five stages, including examples that provide empirical support or may include the psychological and theological meaning of therapeutic action. The distinctiveness of these guideline is in its modification specifically designed for mothers of children with disabilities based on significant qualitative research and its integration with emotion-focused therapy.

By offering narrative therapy that is specifically designed for mothers of children with disabilities, my intention is to help mothers be explicitly aware of their agency and their practical wisdom and thus be empowered to employ both wisdom and power more confidently, and with

intention. The goal of this map of narrative practice for mothers is to identify the practical wisdom in mothers' narrative as it was described in the previous chapter, guide mothers to acknowledge its existence, and point out a positive function for mothers' subjectivity as they support their children. In recognizing their practical wisdom, mothers will become aware of their own sense of agency which will lead to intentional execution in their daily lives. I want them to *see* themselves as agents of this activity of "mixing and matching" different worldviews of disability. Rather than being swayed by any particular worldview, being aware of the sense of agency to manage different worldviews as needed can strengthen mothers' sense of agency. This also will give rise to the understanding that the various worldviews related to disability are not essential but constructed, that each provides one way to look at disability. Each one has a different degree of predominance and usage. Finally, mothers and their caregivers need to be convinced that the chosen form of mothers' practical wisdom is not only possible but good.

A critical question can be raised: If mothers are already utilizing practical wisdom as I have argued in chapters 5 and 6, what is the use of this guide? In reality, while mothers employ their 'practical wisdom,' most of them do not seem to be aware of doing so. They don't know how to use their practical wisdom intentionally as a tool. Their wisdom comes from their lived experiences; their insights are not systematized, not conceptualized. The practical wisdom that they have is subjective; my purpose is to bring it into a more conceptual, generalizable frame. How can we take this subjective learning and use it in other situations? Furthermore, through this therapeutic map I wanted to help mothers create space to process and reflect on their emotions and experiences if they are available. Research has consistently shown one of the major challenges of parents of children with disabilities is having "less time or psychic space to allow

for reflection on their present situation due to the complexities and demands on them.”<sup>1</sup> This can lead mothers to be less emotionally available for their children in their development. Increasing emotional awareness through providing these kinds of therapy can positively influence these mothers to be more accepting of reality and to be more emotionally available for their children.

In addition, as described in Chapter 2, current theological resources are not sufficiently affirming of mothers’ lived theology; mostly theological voices are telling mothers what they are doing is wrong. In this context, an intervention is necessary in order to clarify and amplify and make this wisdom more useful in an intentional way.

Narrative therapy is ultimately intended to weave a new narrative by focusing on the different worldviews of *mothers* instead of their children and those with whom they have relationships. Through engaging in narrative therapy, they can learn that the problem or predicament of the disability of their children is part of a worldview. And that the meaning of disability is not static or fixed but changes, depending on which worldview they utilize. Furthermore, mothers will be able to choose, without conflict or tension, their most-preferred understandings of disabilities in different contexts, based on their conceptions and experiences regarding certain worldviews. Ultimately, and most importantly, through this process, mothers will gradually become aware of their own sense of agency, especially in that they are the one who can best define the meaning of disability. Affirming the various understanding of disability is intricately connected to affirming their own experiences – social connections, cultural upbringings, education, and inner-beliefs on disability. Hence, I argue that narrative therapy is an effective therapeutic tool that promotes mothers’ psychological and spiritual well-being as well as it promotes and strengthens a mother’s living human web of worldviews and their practical

---

<sup>1</sup> Harvey, “Maternal Subjectivity,” 97.



wisdom. Narrative therapy can assist mothers to excavate, explore, recognize, and affirm various worldviews in regard to their understanding of disability.

Lastly, I would like to help mothers become better able to clarify the worldviews with which they have built relationships and to understand that this relating to multiple worldviews and building relationships with worldviews is normal and can be considered good. The ideal picture I draw is one of both caregiver and mother reaching the point of *seeing* even seemingly contradictory worldviews of disability playing together like an orchestra with each mother being the conductor.

Before proceeding into details, it is important to refresh the ontological and philosophical assumption upon which this dissertation is based that I mentioned in Chapter 3. The common presumption of the research methods is that we live in a reality that is constructed. In chapter 4, 5 and 6, I described and analyzed mother's lived theology that was constructed within each one's reality. The research method I specifically used—discourse analysis, narrative inquiry and narrative therapy—are all commonly based on the understanding that one's conceived reality is constructed whether a person is aware or not. If one's reality is constructed, it is not essential; that means it is possible to deconstruct and rebuild. The ultimate goal of this constructive proposal is to offer therapeutic space that generates experience, a reality. Angus and McLeod also describe psychotherapy in a similar vein, as “a specialized discursive activity designed to help clients shape a desired future and reconstruct a more compassionate and sustaining narrative account of the past.”<sup>2</sup> I strongly agree and also believe that the relationship care giver and care seeker build in a therapeutic setting can become a seed to create an experience to serve the care seeker.

---

<sup>2</sup> Lynne E. Angus and Leslie S. Greenberg, *Working with Narrative in Emotion-Focused Therapy: Changing Stories, Healing Lives* (Washington, DC: American Psychological Association, 2011), 3–4.

## **Transitional Space as a Therapeutic Space**

Winnicott's notion of transitional space best describes this experience in therapeutic space. What takes place in this therapeutic space has a great deal in common with a notion espoused by Donald Winnicott, a British psychoanalyst, of a transitional space that is also called an intermediate area. Winnicott's term was originally used to describe the "phase of an infant's development when inner and outer reality begin to become apparent."<sup>3</sup> It is transitional in that a young baby finds an object that is, for example, her mother, a thumb, or another object.

Winnicott saw that this transitional space entails imagination because in that moment the infant is seeking something other than his or her mother. For example, the infant will also seek to find a thumb or a blanket, or a teddy bear. This relationship with a transitional object "represents a continuity of experiences that the baby needs."<sup>4</sup> Winnicott saw, in this context, the role of "good-enough mother" is to provide "a near-perfect environment, allowing the baby the illusion of unity and omnipotence"<sup>5</sup> in that the baby's first experience with space is mediated through an attachment with the baby's mother. This illusion and creativity in taking whatever object as mother figure is necessary, for Winnicott, for baby to survive and is essential in the infant's process of becoming able to recognize reality.<sup>6</sup> The term is used most often to explain a space where a person can freely play without restriction, can navigate and explore her own psychological and external realities.

---

<sup>3</sup> Jennifer Johns, "Transitional Object, Space," in *International Dictionary of Psychoanalysis*, Encyclopedia.com, November 29, 2022, <https://www.encyclopedia.com/psychology/dictionaries-thesauruses-pictures-and-press-releases/transitional-object-space>.

<sup>4</sup> Johns, "Transitional Object, Space."

<sup>5</sup> Johns, "Transitional Object, Space."

<sup>6</sup> Johns, "Transitional Object, Space."

Transitional space (inter-intermediate are, third area, potential space) is a space of experiencing, between the inner and outer worlds, a space that is contributed to by both, in which primary creativity (illusion) exists and can develop.<sup>7</sup>

This concept of transitional space has expanded to mean a space “in between” that goes beyond binary thinking unlike the ordinary thinking of most psycho-social researchers: “external and internal, objectivity and subjectivity, social and personal, positioning and agency, construction and reality.”<sup>8</sup> The idea has been applied to different contexts for example, “Winnicott included religion under the rubric of transitional phenomena.”<sup>9</sup> Ryan LaMothe posits that Winnicott’s theory of development can explain healthy and unhealthy aspects of religion. What is most relevant to my dissertation is that Winnicott draws an analogy of this transitional space to the therapeutic situation as it is the space where the patient’s (in Winnicott’s term) world and the analyst’s world overlap.<sup>10</sup>

Mary Moschella saw the devotional practice of Italian immigrants in San Pedro as offering a transitional space that supports their psychological and spiritual dimension.<sup>11</sup> I see this concept of transitional space as a useful and effective metaphor to describe therapeutic and caregiving space for mothers. The metaphor of immigration in describing the experience of such mothers is not mine; it has been used as a popular metaphor to provide some support and understanding that helps mothers to make sense of the situations they encounter as seen in the introduction.<sup>12</sup> When applying a worldview frame that I presented in Chapter 5, most likely when

---

<sup>7</sup> Donald Winnicott, “Playing and Reality,” *International Journal of Psycho-Analysis* 34, Part 2 (1953): 9.

<sup>8</sup> Wendy Hollway, “In Between External and Internal Worlds: Imagination in Transitional Space,” *Methodological Innovations Online* 6, no. 3: (2011): 50–60, <https://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.690.3724&rep=rep1&type=pdf>.

<sup>9</sup> Ryan Lamothe, “Winnicott and Helplessness: Developmental Theory, Religion, and Personal Life,” *Psychoanalytic Quarterly* 83, no. 4 (2014): 871–96, <https://onlinelibrary.wiley.com/doi/full/10.1002/j.2167-4086.2014.00125.x>.

<sup>10</sup> Johns, “Transitional Object, Space.”

<sup>11</sup> Mary Moschella, “Mary Star of the Sea: The Interplay of Immigration and Religion in Italian Catholic Devotional Practices in the Port of Los Angeles,” abstract (PhD diss., Claremont School of Theology, 2001).

<sup>12</sup> Kingsley, “Welcome to Holland.”

mothers first meet their children with disabilities, the worldview in which they had lived suddenly requires some major modification to accept and understand their experiences with their children and their children. Being parents to children with disabilities opens up radically different worldviews by cracking up and pointing out the limitation of their then-operating worldview. Mothers are to some degree forced to move to a different reality which requires different worldviews to complement the limits of the status-quo-operating worldview. It is at this point that I think transitional space is needed; for mothers to be able to explore, and to play freely within their previous reality and current reality, and their psychological reality and reality they have experienced so far.

For instance, as we saw from the case of Alice and Karyn, both mothers in reality are heavily influenced by the medical worldview and—given the benefits it brings to their lives to some degree—this choice is, to some degree, inevitable. It is easy for a person to choose a way of thinking about what is most useful and effective to a given situation. In other words, in mothers' external reality, there are invisible restrictions as to what kinds of worldviews mothers are employing. The transitional space becomes a space allowing mothers to play with their worldviews without realistic restriction.

Winnicott asserts that the experience of transitional space not only provides mothers with the ability to confront the outer reality but it also offers relief from the strain caused when a person tries to make sense of conflicting inner and outer realities. According to Winnicott,

The task of reality acceptance is never completed, ... no human being is free from the strain of relating inner and outer reality, and ... relief from this strain is provided by an intermediate area of experience which is not challenged.<sup>13</sup>

---

<sup>13</sup> Winnicott, "Playing and Reality."

As such, through this transitional space, mothers gain a space and time where they can try out different worldviews without tension, in rather a playful manner, if possible, than they experienced in their reality. Furthermore, through exploring the worldviews, mothers can learn about themselves through exploring worldviews about which they care the most, including how she makes meaning, and what she has learned about disability through her own life.

### **The Role of the Caregiver**

From Winnicott's perspective, the role of care giver can be likened to the role of mother. As a good-enough mother provides a near-perfect environment that allows baby to hold imaginative objects, the good-enough care giver's role is to offer a space in which the one cared-for can freely explore their psychological attachments with whatever worldviews they have held. A care giver's ability to be present, to understand and listen to a careseeker's stories, both affirms and validates the other and will function as exemplary to careseekers. Thus, careseekers will likely learn from the way care giver treat the careseekers. In the counseling practice, this kind of understanding of the care giver's role is common as Angus and Greenberg point out:

These relationship qualities are seen as the means by which the working alliance is established and maintained, as well as the means by which the therapist helps clients to engage with particular kinds of emotional processes for symptom reduction, interpersonal problem solving, and new meaning making.<sup>14</sup>

As such, it is not only the contents of conversation that affect the careseeker but the quality of the relationship will influence the quality of care received. In this particular context, the more a care giver allows room for a careseeker to play with various worldviews in her psychological and external reality, the more the careseeker can process her own knowledge about disability and the experiences pertinent to that knowledge.

---

<sup>14</sup> Angus and Greenberg, *Working with Narrative*, 6.

A care giver who employs narrative therapy does not take the stance of an expert; rather the care giver positions herself or himself as co-author “in investigating problem narratives and with constructing alternative”<sup>15</sup> narratives out of the substories of persons’ lives.<sup>16</sup> The care giver takes a stand to advocate for the careseeker, especially against what is considered by the careseeker as “problems.” In order to take this stand, narrative therapists maintain a distance from the careseekers’ stories in order that they not be persuaded by the story’s problem as they explore what is embedded in the problem stories. It is through this distance, ironically, that the care giver and care seeker take a stand together against the problem.<sup>17</sup>

More specifically, by focusing on the problem, care giver interprets the dynamics observed between a person and a problem as a microcosm of politics. For Michael White, a founder of narrative therapy, “the personal is and must be, deeply embedded in the political.”<sup>18</sup> From narrative therapy’s perspective, what happens in human relationships, in the emotions of our daily lives, which include our personal struggles and our hopes and dreams for self-realization and happiness, are “also unmistakably tales of power politics.” These are seen as the “politics of local relationship as well as the larger social politics of gender, class, professional, and institutional dominance.”<sup>19</sup> From this perspective, it will be of interest to care seeker if the care giver is aware of the dominant discourses as those appear to function, either in or against the interest of the careseeker.

Rogers and Perls summarizes the above relational quality and skill-oriented quality as:

---

<sup>15</sup> Christie Neuger, *Counseling Women* (Minneapolis: Fortress Press, 2001), 90.

<sup>16</sup> Neuger, *Counseling Women*, 90.

<sup>17</sup> Neuger, *Counseling Women*, 90.

<sup>18</sup> Neuger, *Counseling Women*, 89.

<sup>19</sup> John Winslade and Lorraine Smith, “Countering Alcoholic Narratives,” in Gerald Monk et al., *Narrative Therapy in Practice: The Archaeology of Hope*, 174–76, quoted in Neuger, *Counseling Women*, 89.

*Being with the client* (i.e., being fully present and bringing specific relationship qualities to bear) was combined with *doing things with the client* (i.e., guiding the client through a process of change) to form a new style of practice.<sup>20</sup>

While it is important for care giver to guide the conversation with specific goals it is also significant to follow the guide of careseeker, follow the flow and be opened to be guided by careseeker, during the therapeutic conversation.

The transferable proposals include guiding ideas for therapeutic conversations and a map of narrative practices for mothers of children with disabilities,<sup>21</sup> one that is especially useful for professional care settings.<sup>18</sup> Because this proposal is primarily based on narrative therapy, this proposal would be most useful for professional care givers who do caring works using the narrative paradigm—for example, those who are in a variety of spiritual caregiving positions, including ministers, chaplains and counselors, but especially those who understand the philosophical strength of narrative therapy. Care givers in these professional positions often have designated authority, commitment, time, space, expectation, and protocol to observe. Therapeutic conversation needs to be protected with these rules. These rules exist to protect the vulnerability not only of the careseeker but also of the care giver as a human being while dealing with emotionally sensitive human experiences. I do not encourage this proposal, although from the outset it may seem like a simple conversational tip, to be used in any non-professional caring setting.

---

<sup>20</sup> Rogers and Perls (1951), quoted in Angus and Greenberg, *Working with Narrative*, 6.

<sup>21</sup> Michael White, *Maps of Narrative Practice* (New York: W. W. Norton & Co., 2007). I borrow the term ‘map of narrative practice’ from Michael White. However, in developing this proposal I have been mindful of its use by groups of people beyond therapists—in particular those who are not disabled who want to explore their understanding in relation to disability. However, it can be used to refer to a person’s understanding of others in her own mind.

### **Invitation to Tell the Story**

Inviting mothers to tell their stories is the very first step for this therapeutic conversation. A majority of mothers of children with disabilities spend most of their time caring for their children or arranging for the care of their children. Much of the time their minds are occupied with their children. The pragmatic demands and that pattern of thinking and life have become a habit that drives everyday life. Research suggests that parents of children with disabilities seek less of a religious/ spiritual or psychological resource for themselves as they conceive that taking care of their children is priority and once they prioritize taking care of their children, they find themselves having less time for themselves.<sup>19</sup> However, as we saw from the thick description of Alice and Karyn, these mothers go through the turmoil of emotions to the degree that facing their children with disabilities can become traumatic experiences. Intervention in emotional and psychological support can assist mothers through the process as seen from the processes of Alice and Karyn.

For this reason, it is important, to signal that the time for the therapeutic conversation is meant to be time for mothers themselves and to provide assurance that this time and space will be for her. Another factor that needs special consideration for mothers of children with disabilities is the explicit assurance that what is told in this session will be confidential. The legal limitations of confidentiality agreements will be communicated in the intake interview to protect both careseeker and caregiver. There are multiple reasons behind this. First, mothers have become used to experiencing some kind of unfairness as the result of their children's disability. This unfairness can range from practical matters to emotional reactions such as strange gazes.<sup>20</sup> Mothers can be concerned if sharing their children with disability might cause any harm or discrimination. Second, studies have pointed out that when family is faced with a child with



disability they likely feel anxiety, fright, guilt, humiliation and shame.<sup>22</sup> Among these, the senses of guilt and shame are prominently observed.<sup>23</sup> Studies agree and Alice and Karyn showed in chapter 4 that it is almost a traumatic event, one even described to have a similar degree of emotional stress and impact as does bereavement.<sup>24</sup>

These emotions require extra sensitivity to ensure that the caregivers of mothers feel safe so that they can share their feelings of shame. These factors might have intervened in mothers' day-to-day lives and to some degree function to police the content of what they say and to whom they say it; and in extreme cases, to affect their way of thinking. The fear of any penalty or of feeling shame can hinder any genuine emotion and thereby inhibit the processing of some experiences. For this reason, it is important to explicitly mention that this space and time in therapeutic conversation is qualitatively different from their casual conversations. That this place is safe and confidential in so far as it is within the scope of the limits of the confidentiality agreement. Communicating about and briefly introducing this basic feature and condition of therapist/client conversations can help mothers to explore, to be aware of and to express "their own truths without fears about what they 'should' be saying in order to maintain relationships and avoid harm."<sup>25</sup> In this way, providing this information can be the beginning of the necessary care of mothers. The religious notion of 'sacredness' can be useful here, if mothers are familiar with this term, so that mothers know they have a separate space that is distinguished from their daily lives. For example, in the religious setting, candles are lighted, music is played, ministers or those in positions of religious authority wear their professional gowns.<sup>26</sup> These are signals that

---

<sup>22</sup> Harvey, "Maternal Subjectivity," 94–95.

<sup>23</sup> Harvey, "Maternal Subjectivity," 94–95.

<sup>24</sup> Harvey, "Maternal Subjectivity," 94–95.

<sup>25</sup> Neuger, *Counseling Women*, 127.

<sup>26</sup> Mary Clark Moschella, *Caring for Joy: Narrative, Theology, and Practice*, Theology in Practice (Leiden, Netherlands: Brill Academic Publishers, 2016), 254.

symbolize that this is a ‘different space and time’; it is sacred. Now that the signal of this time and the space’s sacredness and the assurance of confidentiality have been communicated, it is time for mothers to share their stories.

Mothers can likely feel uncomfortable telling or beginning to tell—or may even feel uncomfortable with-thinking about—their own truths. In these cases, what will be helpful is to ask mothers what they feel at this moment within their bodies. Asking this question, having mothers inquire, “How does my body respond or react in this moment?”<sup>27</sup> and encourage mothers to attend to their body’s condition, provides a good starting point for the exploration of their inner world. This process—becoming aware of her bodily condition—can help release any anxiety she is feeling at the moment. Dr. Nichole LePera—whose work focuses on daily experiences of trauma—asserts the importance of being aware of the needs of our bodies. LePera states, “Healing starts with learning how to tap into the needs of our body and reconnecting with our intuitive Self.”<sup>28</sup> Attending to our body can be one way to reach our intuitive self. “It begins with the act of witnessing.”<sup>29</sup> These questions suggested by LePera are helpful:

- “How is my body reacting?”<sup>30</sup>
- “What does my body need?”<sup>31</sup>

In the beginning, it is important for a caregiver to intentionally choose broad questions to ask and to control the extent of questions, so they do not become too intrusive. Questions can be light in the beginning, which is appropriate, considering that the two people, care giver and careseeker, have just met. The caregiver must pay attention to the care receiver’s emotional state

---

<sup>27</sup> Nicole LePera, *How to Do the Work: Recognize Your Patterns, Heal from Your Past, and Create Your Self* (New York: Harper Wave, 2021), locs. 87–120, Kindle.

<sup>28</sup> LePera, *How to Do the Work*, loc. 89 of 294, Kindle.

<sup>29</sup> LePera, *How to Do the Work*, loc. 89 of 294, Kindle.

<sup>30</sup> LePera, *How to Do the Work*, loc. 89 of 294, Kindle.

<sup>31</sup> LePera, *How to Do the Work*, loc. 89 of 294, Kindle.

and choose and ask questions based on that. The care giver must continue to show attentiveness and curiosity and to use inviting gestures. While the caregiver listens to the careseeker's story, the care giver must pay attention to any emotional change within the careseeker. Some careseekers might show a defensive stance, and others might show emotional responses that are partly caused by unresolved challenges or emotions that are precisely the reason this therapeutic session is needed. We begin with broad questions, such as:

- How are you today or these days?
- Could you tell me about yourself?
- Have you had any experience of counseling before?
- What is the most pressing issue these days?
- What brought you here?

When the care giver begins to sense a change of mood that indicates the careseeker is beginning to feel more comfortable and become willing to tell their stories, the therapist can begin to ask more direct questions related to the child's disabilities such as,

- How is it to be a parent of a child with disabilities?
- Tell me how your child is doing?
- How is your family doing?

The major goal is to thicken the story, to add specific information of the story by using "the details of the setting, context, characters, and emotional currents in the story."<sup>31</sup> The details of the story can be gained with the listening skill of 'probing,' not limited to counseling. It is helpful to intentionally come up with open-ended questions such as:

- What else was/is going on in this story?<sup>32</sup>

---

<sup>32</sup> Wimberly, *Recalling Our Own Stories*, 4–5, quoted in Moschella, *Caring for Joy*, 255. Wimberly takes this term from Adrian van Kaam, *Religion and Personality* (New York: Doubleday, 1968), 20.

- What was/is this like for you?<sup>33</sup>
- Who else was there? How did they act?<sup>34</sup>
- What do you make of this development?<sup>35</sup>
- Were there any rules you were following?<sup>36</sup>

When the detailed texture of the story emerges, the care giver needs to begin to pay close attention in order to read whatever “underlying beliefs, plots, and subplots surface.”<sup>37</sup> In doing so, care giver need to pay attention to both the events and the meanings of those events to careseeker.<sup>38</sup> Moschella calls this the “story’s overarching plot” and quoted Wimberly who called it the “project of existence.”<sup>39</sup> What this means is something like a sense of purpose<sup>40</sup> or a broad theme s that drives a person’s sense of being.

By guiding the careseeker through the aforementioned process, a therapist has to be a constructive and sensitive listener. Stories, as they begin to be told by careseekers, may not be in a familiar, conventional, narrative form of introduction-conflict-resolution-conclusion, nor thematically organized. The stories told by mothers may be about some point in the past or present, and they may switch back and forth between the past and present. Furthermore, the careseeker is likely to tell stories with many vignettes and will probably include issues, problems, challenges, desires, and overwhelming or familiar emotions such as loneliness, shame, or anxiety.<sup>40</sup> This is because this therapeutic conversation is likely to be the rare chance for mothers to be able to reflect on their thinking and experiences on disability. Also, this rather

---

<sup>33</sup> Moschella, *Caring for Joy*, 255.

<sup>34</sup> Moschella, *Caring for Joy*, 255.

<sup>35</sup> Moschella, *Caring for Joy*, 255.

<sup>36</sup> Moschella, *Caring for Joy*, 255.

<sup>37</sup> Moschella, *Caring for Joy*, 255.

<sup>38</sup> Moschella, *Caring for Joy*, 255.

<sup>39</sup> Moschella, *Caring for Joy*, 255.

<sup>40</sup> Moschella, *Caring for Joy*, 255.

sporadic recalling of memories can be a good sign in that it shows mothers responses are honest, intuitive and spontaneous rather than carefully curated or intended/articulated. This is the point where a narrative therapist can intervene and take on her role of helping the careseeker reorganize her story by using all the stories, information, emotions shared by careseeker as material with which to create the most authentic and meaningful story for the careseeker. With these careseekers' rather rough stories, once a caregiver begins to notice signs of the careseeker's operating worldview, it is time to identify the various worldviews of disability that function in each mother's narrative.

Other therapeutic activities, techniques, or tools—for example, the various arts such as music or paintings—can be effective as prompts to elicit the careseeker's emotions or to reveal the hidden story. For example, Josh Morris, pastoral theologian whose works focuses on moral injury, in his dissertation research, has explored how music functions for Phillip, a veteran, in bringing him back emotionally from his experiences of war and helping him to process his stories of war.<sup>41</sup> Morris writes, "The telling of a war story is not always a verbal affair."<sup>42</sup> But it can involve different mediums such as music. This can be the case for Alice, to whom art is an integral part of her life. Meaningful activities of art can help open the careseeker's heart and can become a powerful medium through which to communicate her experiences and emotions. For this, it would be helpful at the beginning when asking general questions to ask what the careseekers are interested in or what they do in their free time.

Furthermore, in this stage, different incidents or events in relation to a child's disability will be told. The caregiver will begin to see glimpses of the careseekers' understanding of

---

<sup>41</sup> Joshua Thomas Morris, "Narratives of Military Moral Injury and Reintegration: Toward a Critical, Liberative Practical Theology" (PhD diss., Claremont School of Theology, 2019), 204.

<sup>42</sup> Morris, "Narratives of Military Moral Injury," 204.

disability through these different incidents or events. Their various understandings may either be explicitly mentioned by them or their understandings can be underlined by the tone of the stories they share. One way to see these glimpses is to identify associated major institutions, people with whom they interact, and feelings about disability itself and about their children's disabilities. When care giver comes up with a several candidates of possible operating worldviews in hand, it is time to move on to the next stage.

### **Identifying Worldviews in Mothers' Stories**

This section will deal with three stages: 2. Identifying the worldviews, 3. Mapping the influence of worldviews on mothers and 4. Evaluating the influences of worldviews on mothers. Their purpose is ultimately to externalize the worldviews so that mothers can be aware of the conceptual separation between worldviews and themselves. With this in mind, the specific goal of this phase is to identify operating worldviews in mothers. Through the previous stage, the care giver has probably gathered some clues from the careseeker's narrative about what kinds of perspectives are functioning or could possibly function in that narrative. The care giver can begin to categorize stories into perspectives in her own mind or make notes. However, this categorization does not need to be shared with the careseeker at this point because in this phase the focus of both the care giver and careseeker is to work together to explore the stories as they emerge and the related emotions as a way to identify various perspectives.

In the beginning, the identification of each worldview doesn't need to be clear. The care giver will begin to guide the conversation to help unpack the careseeker's ideas about disability with below questions.

- When did you first learn about disability?

- What is it like to experience the disability of your own child?

As the careseeker explores her stories, the care giver pays particular attention to the task of figuring out various worldviews. It will be difficult to expect the careseeker to use the concepts of worldviews. Most likely, it is better for the caregiver to guide the conversation in a way that helps the careseeker to tell her story; and through these collections of stories and episodes the care giver can infer the careseeker's perspective of disability. Careseekers' various experiences, emotions and thoughts become sources that enable the care giver to discern to which worldview this idea on disability belongs. Although in appendix A I delineated most possible types of worldviews, there are other worldviews that are not identified here. In those cases, I encourage the care giver to still identify this idea and name it by using the context of the careseeker. In some cases, the care giver may want to suggest a general worldview, because the careseeker's stories do not clearly distinguish a specific one. In this case, care giver may have several candidates given the stories told by careseeker. The care giver makes notes with a few key words that identify ideas or emotions. Then, the care giver can probe more deeply into each different understanding of disability. Gradually, the care giver can ask more direct and concrete questions based on the stories shared by a specific careseeker. For example, a care giver can ask clarifying question such as,

- Did you mean that disability means X to you in this specific context?
- When you said X, do you think your underlying thought on disability is Y?

Asking what the careseeker considers to be a problem when it comes to her children or a specific disability can provide insights that help the care giver to infer and identify the careseeker's operating worldview. For this, using the therapeutic conversational skills from solution-focused therapy can help the therapist identify the most important and meaningful

worldviews for mothers. One of the most effective therapeutic conversational skills is this question: “If you lived in wonderful world where everything was possible, what wonderful thing would you hope could take place?”<sup>43</sup> The answer to this question usually involves resolving something about which the careseeker feels unsatisfied.<sup>44</sup> Having the careseeker answer this question can ironically help the careseeker to see more clearly what careseeker considered most problematic in her life. Thus, the answer can provide the caregiver with a clue to the mother’s worldview. Here, we see connection with Lester’s insight into people’s hopes that can function as resources to assess their psycho-spiritual well-being that I described in Chapter 2, Literature Review. The fundamental principle behind the above solution-focused therapy is congruent with White’s idea to pay attention to implicit and untold stories in White’s term, it is “double listening.” According to White,

For example, if a person has the experience of frustration, he or she must be pursuing purposes, values, or beliefs, but not attaining them. If a person experiences despair, he or she must have hopes, dreams, or visions of the future that are not being fulfilled. If a person experiences injustice, he or she must have a conception of a just world (White, 2003). It follows that if a person is speaking at length of frustration, we can ask questions that invite him or her to notice the purposes, values, and beliefs that are being frustrated, and so on.<sup>45</sup>

This is possible because White describes when we make meaning of certain experiences it is most likely in relation or in contrast to other experiences.<sup>46</sup> When we make meaning of certain experience it is dependent on other experiences, especially in relative terms. White points out that we think or feel “this is different from . . .”<sup>47</sup> “This means that a single description of any experience can be thought of as a figure that we can see because of a contrasting background. A

---

<sup>43</sup> Paul Hanton, *Skills in Solution Focused Brief Counselling and Psychotherapy* (Los Angeles: SAGE, 2011), 77–84.

<sup>44</sup> Hanton, *Skills in Solution Focused Brief Counselling*, 77–84.

<sup>45</sup> Combs and Freedman, “Narrative, Poststructuralism, and Social Justice,” 1041.

<sup>46</sup> Combs and Freedman, “Narrative, Poststructuralism, and Social Justice,” 1041. The authors draw on their reading of Gregory Bateson (1980), Jacques Derrida (1978), and Michael White (2000).

<sup>47</sup> Combs and Freedman, “Narrative, Poststructuralism, and Social Justice,” 1041.



story about a problem is made in contrast to some experience that is preferred and often treasured.”<sup>48</sup>

Engaging in double listening invites the care giver to pay attention to any implication of the stories and use inferences to deepen the exploration of the narrative of careseeker. “These implied experiences are a rich source of preferred stories.”<sup>49</sup>

Through this process, the care giver may begin to recognize multiple worldviews of disability woven together in a unique way, within the living web of worldviews, as we have seen in the stories told by Alice and Karyn. Individuals may incorporate similar worldviews, but each is shaped by the individual’s own experiences and backgrounds, which makes each of the person’s living web of worldviews distinct. While going through the process of identifying the worldviews, the care giver can begin to use a relationship framework and use relational language. This can prepare for a smooth transition to the next stage—for example, the careseekers’ relationship with the medical worldview.

When a care giver feels that there are prominent identifiable worldviews, then the care giver can communicate that with the mother, discuss it whether or not the mother is in agreement; if not, explore why and find a way to come to an agreement as to what kinds of worldviews exist in the mother’s narrative which can help the careseeker to be aware of those perspectives. Furthermore, this is the point where the care giver can identify the mother’s practical wisdom.

Through the task of identifying worldviews, the intention is to conceptually separate the worldviews from the careseeker. Once the worldviews are identified within the relationship between careseeker and care giver, we can say that the process of externalization has begun.

---

<sup>48</sup> Combs and Freedman, “Narrative, Poststructuralism, and Social Justice,” 1041.

<sup>49</sup> Combs and Freedman, “Narrative, Poststructuralism, and Social Justice,” 1041.

Many pastoral/practical theologians who appropriate narrative therapy into the field of spiritual care agree that the strength of narrative therapy is in its separation of a problem from a person. I strongly agree with this. It is because this conceptual separation enables a person to imagine herself without any problem. Then, at least for a moment, the person is able to get a feeling or glimpse of what her life would be without the problem. The notion of problem is most likely rooted in or in relation to the individual's worldviews. As such, the meaning and interpretation of disability is deeply connected with the worldviews people hold. Separating the worldviews, can allow a person to see the arbitrariness of the various meanings of disability and can provide a psychological space in which a person can separate any worldviews related with disability and provide a space for a sense of self. If this detachment doesn't take place, it is most likely to personalize the problem of the specific worldview that a person deeply believes.

The prime exemplary worldview is the medical worldview. The character of the medical worldview essentializes the meaning of disability. Seeing disability in this light imbues it with the meaning and interpretation of a medical disability. Thus, admitting the predominance of the medical worldview enables a person to see disability as only one among other worldviews. This will enable a person to deconstruct the unconscious belief about the absoluteness of the definition of disability. Knowing the arbitrariness of various understandings of disability allows a person to detach related worldviews and to imagine her world at least for a moment without the worldview being imbued with any specific beliefs. To reframe the famous statement of narrative therapy, 'The person is not the problem. The problem is the problem.' I would say 'The person is not the worldview. The worldview is the problem.'

This externalization is the beginning of a protest to the problem, according to Karl Tomm, who wrote "The Courage to Protest: A Commentary on Michael White's Work" (1993).

It not only “averts the reactionary response that inevitably results from a protest directed against a person, but also opens space for that same person to join him in the protest against the problem.”<sup>50</sup> Furthermore, this protest involves a shift in power dynamics for a careseeker to stand above the problem from subordinating to a problem.<sup>51</sup>

According to White’s thinking, problems are not invented by people.<sup>52</sup> Rather, people “are recruited into actions and ways of thinking that create problems.”<sup>53</sup> As such, a worldview is not something people create; instead they have been recruited into the way of thinking and actions of certain worldviews. In the next stage of mapping the influence, with the identified worldviews, the caregiver will ask questions to bring to light the ways that people have been recruited into worldviews.<sup>54</sup> The effects of various worldviews operating in mothers’ minds, on their lives and relationships will be closely examined.

### **Mapping the Influences of the Worldviews**

Mapping the influences of the worldviews considers each worldview as an independent entity that has its own life. This stage involves exploring *the lives of* worldviews at play in mothers’ narratives by exploring the birth, support system, its effect, the relationship mothers build with the worldviews and mothers’ responses to the worldviews. Now that both care givers and mothers are in agreement about what kinds of worldviews mothers held in their stories, in this stage it is time to thicken the stories by exploring details such as the various emotions mothers felt and the intentions and responses of the mothers to each worldview. This phase

---

<sup>50</sup> Karl Tomm, “The Courage to Protest: A Commentary on Michael White’s Work,” in *Therapeutic Conversations*, ed. Stephen Gilligan and Reese Price (New York: Norton, 1993), 63–64, quoted in Combs and Freedman, “Narrative, Poststructuralism, and Social Justice,” 1053.

<sup>51</sup> Combs and Freedman, “Narrative, Poststructuralism, and Social Justice,” 1053.

<sup>52</sup> Combs and Freedman, “Narrative, Poststructuralism, and Social Justice,” 1054.

<sup>53</sup> Combs and Freedman, “Narrative, Poststructuralism, and Social Justice,” 1054.

<sup>54</sup> Combs and Freedman, “Narrative, Poststructuralism, and Social Justice,” 1035.

involves two key tasks: 1. To map the influences of the worldviews in careseekers lives and 2. To explore what kinds of relationships mothers have with these worldviews. There is wiggle-room in terms of the order of these two tasks depending on the flow of the conversation. One can do the first task and the second task in numerical order or one can explore both tasks by combining these two tasks. In the process of mapping the influences of worldviews in mothers' lives, the care giver must make sure that they begin to operate within the relational framework. That is, they must see mothers as having relationships with each worldview.

I mentioned in the beginning of this chapter that the narrative care giver must adhere to the belief or at least consider the possibility that the careseeker is an expert of their own lives. Particularly in this stage, this aspect becomes more prominent than in other stages, because the care giver is fundamentally curious about how these different worldviews affect the careseeker and this can be explained only by the careseeker. In this stage, mothers prominently become knowledgeable about their worldviews. They will share what was it like for them to have a certain relationship with a worldview or remember when they were most likely involved in certain worldviews. It could be not easy to articulate right away how different worldviews influence their lives. In this case, as I have guided careseekers to pay attention to their bodies in the beginning, the same strategy can be used. It is to guide care seeker to pay attention to their bodily reaction when thinking of certain worldviews. This can be a very helpful way to begin the exploration.

First, the care giver tracks the history of the worldview by collecting a series of thick descriptions<sup>55</sup> from the careseeker, for which White uses the metaphor of investigative reporter. Dividing the history of the worldview into its creation and life can help the care giver to explore

---

<sup>55</sup> Moschella, *Caring for Joy*, 257.

and understand the careseeker's stories. The care giver takes a full account of the birth of the worldview by exploring sources of the worldviews<sup>56</sup> and people involved in the creation of the worldview story.<sup>57</sup> Through this process, care giver and careseeker can both discover the sources and patterns of the worldview's presence in the careseeker's life, "its frequency, its intensity, the conditions of its waxing and waning."<sup>58</sup>

The care giver can begin with simple questions such as the following:

- When did the worldview first come into your life?
- From whom or where did you learn the worldview?
- Can you recall the first encounter with the worldview?

Then, the careseeker asks questions about the life of the worldviews and about what sustains the worldviews—for instance, "the life-support systems" of the worldviews.<sup>59</sup> Through exploring the life-support system of the worldview, both careseeker and caregiver can discover what will function to strengthen certain worldviews:

- When is the worldview most likely to visit you?
- (For a specific worldview) With whom do you most talk about this?

Second, after examining the birth and the life-support system of the worldview, both careseeker and caregiver come to understand the worldview quite well. Then, it is time to take stock of the effect of the worldview on the careseeker. In this phase, the caregiver can more explicitly use the relational framework such as:

- What kinds of relationships do you have with this specific worldview?
- How would you describe this relationship?

---

<sup>56</sup> Moschella, *Caring for Joy*, 257. I modified "the sources of the problem" to "worldviews."

<sup>57</sup> Madigan, *Narrative Therapy*, 74. I modified "problem" to "worldviews."

<sup>58</sup> Moschella, *Caring for Joy*, 257.

<sup>59</sup> Madigan, *Narrative Therapy*, 74. I modified "problem" to "worldviews."

Through these questions the careseeker makes inquiries about the quality of the relationship of the worldviews with the careseeker. When taking stock of the effect of the worldview, it is helpful to divide the analysis into the effect on the person, and into the influences on “different areas of life such as school, home, friendships, and work.”<sup>60</sup> Let me begin with how to explore influences on a person by focusing on emotion.

### Influence of Emotion on the Person

Current literature which focuses on narrative as one of the most indispensable human mechanisms to make meaning reflects the tendency to neglect the emotional affect. However, while therapeutic conversation especially of narrative practice has focused on human beings’ meaning-making aspect, if the emotional issue is not processed adequately, the meaning-making project can be challenged. That is because one’s construction of narrative is usually intricately connected with one’s emotion. L. E. Angus and L. S. Greenberg point out that narrative and emotion are intricately related: “Stories help us make sense of our emotions”<sup>61</sup> and “all emotions are shaped by stories.”<sup>62</sup> Angus and Greenberg saw that narrative processes are important to a healthy integration of affect and cognition that results in “adaptive emotion regulation and the emergence of new views of self.”<sup>63</sup>

Narrative therapy’s assumption is similar in that it sees that people are occupied with a certain limited narrative that is thought to reflect the wholeness of life. In this situation, what is commonly important is to heighten the sense of personal agency over either emotion or limited

---

<sup>60</sup> Moschella, *Caring for Joy*, 258.

<sup>61</sup> Angus and Greenberg, *Working with Narrative*, 4.

<sup>62</sup> Angus and Greenberg, *Working with Narrative*, 4.

<sup>63</sup> Angus and Greenberg, *Working with Narrative*, 6.

narrative.<sup>64</sup> The way Emotion-Focused Therapy (EFT) views emotion is helpful and I think we can integrate that view into narrative therapy because of its shared goal and assumption with narrative therapy. ETF is separate from one's emotions; however, people are occupied or overwhelmed by certain emotions to the degree that they consider certain emotions to be an essential part of themselves. In this case, because they are occupied with emotion, their way of thinking and their behavior are also strongly influenced by emotion.

For this reason, I bring insights from Emotion-Focused Therapy. In their work *Working with Narrative in Emotion-Focused Therapy (EFT)*, these authors assert that integrating EFT with Narrative Therapy yields a profoundly positive therapeutic outcome. EFT understands “emotions as centrally important in the experience of self and in therapeutic change.”<sup>65</sup>

This is particularly relevant to the point when assisting mothers to process their worldviews. Attending to mothers' emotions can fuel processing the worldviews and it is psychologically worthwhile on its own to attend to mothers' emotions for the reasons I will address.

An insight from Clare Harvey, a Senior Lecturer in the Psychology Department at University of Witwatersrand, in her article “Maternal subjectivity in mothering a child with a disability: A psychoanalytical perspective,” is profoundly helpful in gaining an understanding of the emotional current of mothers of children with disabilities. She begins to explain emotional experience of non-disabled people when faced with a disability. The feelings it usually evokes are “highly complex and often contradictory, causing many individuals to be both fascinated and repelled.”<sup>66</sup> and anxiety overall.<sup>67</sup> Studies point out that “disability awakens discomfoting

---

<sup>64</sup> Angus and Greenberg, *Working with Narrative*, 6.

<sup>65</sup> Angus and Greenberg, *Working with Narrative*, 6.

<sup>66</sup> Harvey, “Maternal Subjectivity,” 92.

<sup>67</sup> Harvey, “Maternal Subjectivity,” 92.

feelings” in non-disabled people, “which activates psychological defense mechanisms, which can distort reality and result in a warped perception of the disabled person.”<sup>68</sup>

This perception affects the way a non-disabled person engages with people with disabilities.<sup>69</sup> Mothers of children with disabilities are no exception, of course, to the tendency to project their emotions and assumptions that had been closely associated with the notion of disability in the way they had previously known and experienced them. In Watermeyer’s term, mothers encounter “their own prior ‘discomforting feelings’ about people with disabilities, as well as their sense of how other people might feel about and react to their disabled child, and to them as mothers.”<sup>70</sup> For this reason, it is crucial for mothers to have opportunity to reflect and be aware of their emotion attached to the notion of disability.

Furthermore, mothers of children with disabilities tend to have difficulty being aware of and processing some emotions, especially those that were not encouraged or represented/expressed through society and culture. In the context of relationships, especially those within one’s close vicinity, sometimes, feeling emotion as itself can be difficult because feeling negative or violent emotions can be mistakenly equated with abandoning that person or can evoke the fear of being abandoned. In other cases, it could be that people are not familiar with what they feel, or think it is not permitted to feel what they feel, especially in the context of family. This is especially the case for what usually considered negative emotions: hatred, disgust, anger and such. For example, within the family context, the norm is to not to feel negative emotions toward them. This can happen when one has to carry much of the burden for other family members. Close relationships can hinder the acknowledgement of negative emotions,

---

<sup>68</sup> Harvey, “Maternal Subjectivity,” 92.

<sup>69</sup> Harvey, “Maternal Subjectivity,” 92.

<sup>70</sup> Harvey, “Maternal Subjectivity,” 92.



especially for mothers of children with disabilities. One reason, as noted in Chapter 2, is that there are not enough cultural and spiritual resources specifically designed to address either mothers' experiences with disability or their emotions in connection with those experiences. This is partly because the majority of our cultural images of mothers do not necessarily depict their realities. Mothers are too often depicted with a sacrificial, ever-giving, and happy image of motherhood, which does not fully reflect mothers' experiences. In other words, the given norm for mothers' roles in society is not grounded on the real and complete experiences of mothers. At this moment, what is most misunderstood is that any feeling of distress about their children means these women are not good parents and are guilty of mis-parenting. It is suggested that they do not love their children. Mothers may think that allowing themselves to have any negative feelings about the task of raising their children means they are betraying or abandoning their children. Feeling and acknowledging those feelings of hardship doesn't mean that these women are not good parents. Women can feel 'exhausted,' can realize that parenting is 'difficult,' and feel that the task is sometimes 'too much'—while still loving their children. However, repressed emotions can lead mothers to a number of mental problems and can harm their sense of well-being. Guilt, for example, is one predominant emotion felt by mothers. Suppressed emotions, unfortunately, can lead to mental illness, depression, and such.<sup>65</sup>

I argue that—in mothers' relationships with their children with disabilities—the emotions a person feels can be separated from the relationship itself. More clearly, separation of the emotions and the relationship helps mothers to navigate a better relationship with their children. While mothers process their own emotions, they develop a clear sense of reality in regard to their idea of disability and their feelings for their children. In this context, it will be important for a caregiver to be aware of this possibility and to set particularly intentional goals that allow

mothers to separate the feelings or experiences from the relationship itself. Affirming the emotional aspects of these mothers becomes all the more important when viewing these mothers from the psychoanalytic perspective and considering the specific social location of mothers. Here, I want to particularly emphasize the reason why attention is needed to affirm mothers' emotions.

Then, how can we attend to mothers' emotions and use these as part of spiritual care? Insights from Emotion-Focused Therapy are profoundly helpful. It is not enough to emphasize the importance of affirming one's emotion, it is also important to have the freedom to allow any emotion to be in one's inner world as a transitional space. This is different than allowing the action caused by the emotion. What I mean is to be able to fully allow the presence of any emotions. Allowing and affirming one's emotions can avert the problematic actions that are caused by uncontrollable emotion because the process of affirming one's emotion has the effect of lessening and calming the effect of a specific emotion. Without one's own sufficient affirmation, the emotion tends to become uncontrollable, and one can easily be swayed by it. This is the reason why studies have consistently emphasized the importance of validating and affirming one's emotions, any kinds of emotions, because repressing or denying them can cause severe psychological negative problems that can seriously harm one's well-being, one's relationships, and day-to-day lives.<sup>62</sup> It is because without full acknowledgement and reconciliation, a similar emotional pattern will likely rise again. In L. E. Angus and L. S. Greenberg's words:

A major premise guiding EFT intervention is that we cannot 'leave' a place until we have fully 'arrived' at it. We have to allow ourselves to fully experience what we are feeling in order to heal, and that transformation of maladaptive emotional response happens when we are able to access primary adaptive emotional responses.<sup>71</sup>

---

<sup>71</sup> Angus and Greenberg, *Working with Narrative*, 8.

Here, we need to explore some definitions in order to deeply understand mothers' emotions and reach the therapeutic goals "to increase emotional awareness and to transform maladaptive emotions into adaptive emotional responses that activate adaptive action tendencies and result in new story outcomes."<sup>72</sup> Those terms are: "primary adaptive emotions, primary maladaptive emotions, secondary reactive emotions, and instrumental emotions"<sup>73</sup> These notions will be assessed by care givers while listening to careseekers' narratives.<sup>74</sup>

By employing these four sub-concepts on emotion, the primary goal is for mothers to have the opportunity to access their root experience that has caused the primary emotion that fundamentally arouses certain dysfunctional emotions. By reconnecting with an unresolved primary emotion and generating a new emotional response to the old memory, the acceptance of the unresolved past is generated with the new story. For this the care giver helps the careseeker to disclose, describe and relieve events of core emotional experiences.<sup>75</sup> Through this process, the care giver can help.

Naming an emotion that is evoked in a specific situation or story—be it anger, frustration, or sadness—[it] also has a self-organizing, calming effect that promotes a metalevel awareness of being informed by feeling states and being moved by action tendencies. Too often, we underestimate the power of this simple action of situating and naming our emotion.<sup>76</sup>

Validating one's emotion as itself is also a theological important topic. A therapist can use these strategies during therapy sessions by engaging with these questions. Affirming emotion is also theologically important. Moschella emphasizes the importance of being able to acknowledge and express one's emotion by introducing Gustavo Gutierrez's interpretation of

---

<sup>72</sup> Angus and Greenberg, *Working with Narrative*, 6.

<sup>73</sup> Angus and Greenberg, *Working with Narrative*, 7–8.

<sup>74</sup> See appendix A for definitions of each notion.

<sup>75</sup> Angus and Greenberg, *Working with Narrative*, 6–8.

<sup>76</sup> Angus and Greenberg, *Working with Narrative*, 9.

book of Job. Moschella points out that the book of Job and Gustavo Gutierrez's interpretation reveal the point that "it is right to complain to God and express anger at situations that are wrong, evil, painful, and/or tragic."<sup>77</sup> Moschella further explains, "In this story, Job's honest expression of emotion is not prohibited or punished; in fact, it is seen as a sign of Job's faithfulness, in that he does not dissemble or back down from his belief that his suffering is unmerited."<sup>78</sup>

I'd like to go further. I think the wider perspective gained after this incident is a side effect. What essentially took place in this story is that Job's relationship with God went one step further. Because Job was able to share what he genuinely felt, and was open about it, he was able to trust God to an extent he had never done before. This story can be interpreted as how growth happened in the relationship between Job and God.

Furthermore, affirming emotions closely associated with worldviews can help mothers to accept, understand and process the related worldviews. As one of the fundamental goals of counseling is to help the careseeker to better understand herself, her life story, affirming emotions related to different worldviews can help careseekers to accept their worldviews. While letting the careseeker explore her story, the therapist will likely be noted and observe that mothers are emotionally associated with particular perspectives. This is because narrative and emotion are intricately associated.

When trying to elicit details of the stories related to disability in order to identify the worldviews, paying special attention to emotions described or experienced by careseekers can help processing and advancing mothers in their understanding of their worldviews. It is important to validate mothers' emotion for itself and further when one's emotion is affirmed the

---

<sup>77</sup> Moschella, *Caring for Joy*, 221.

<sup>78</sup> Moschella, *Caring for Joy*, 221.

story closely tied to that certain emotion is more easily accepted, a fact which enables the careseeker to move forward and away from it.

When a person/mother feels certain kinds of emotions, except for situations where it involves abnormal hormones, usually it involves specific objects and specific contexts. When bringing this into my dissertation's context, I would say that mothers' emotion is generated, developed within specific worldviews. That is, when mothers view their children from the perspective of say, the medical worldview, it is almost likely that they will be influenced by a sense of loss, sadness, desperation, humiliation and shame because the standard of human beings is static and from that standardized model of human beings their child with disability falls short. Feeling joy or comfort in the medical worldview is also dependent on the medical worldview. These positive emotions spring from the fact that their children become closer to the healthy understanding of human beings.

If this is the case, then, it will be difficult to solve or deal with certain emotions that hinder their well-being without tackling the fundamental element that has caused the emotions—the worldviews—because when a person is within a certain worldview, it is inevitable that the person will feel the same emotion again. The emotion itself cannot be processed solely without reference to the context. When we think of mothers having relationships with the worldviews, it is easier. This is similar to thinking of relational dynamics within interpersonal relationships.

I think it will be not easy and realistic for caregivers to weaken the maladaptive emotions of careseekers without referencing their worldviews, the context of which cause a person's emotions to arise. However, care givers can help careseekers themselves to see the relational dynamics and the specific worldviews which cause maladaptive emotions. Then, when the maladaptive emotions arise again, the careseeker can think of the emotion within the context of

worldview, and she will know that these emotions are not fundamental but a side effect of what is entailed with the worldview. This thinking tool can help mothers to accept and understand their emotions without much resistance. It provides inner resources to validate her own emotions, because these maladaptive emotions and the worldview are not absolute, but are, in fact, only one type of multiple worldviews. It is just part of herself and one kind of worldview. Emotion needs to be validated in order for a person to move to an emotional next stage. It also opens up her imagination to conceive herself within multiple relationships.

In Winnicott's understanding of object-relationship, it is a false-self. This is congruent with White's assumption on self; self in relationship. Both theorists do not believe the existence of a core self but rather see a self almost always in relation. The psychological sense of liberation offered by this understanding of self is profound.

What is needed to be noted is that not everyone feels or has a similar emotional response to the same worldview. This is because the person's personal background, her interest, personal belief, to what degree she has personally relied on or has considered important certain worldviews are all different from those of other persons. Even with the same understanding of disability, different people will react differently to it. An example can be found in my previous work. In my ethnographic research, I found that different mothers react differently to their own child's disability; some see it as tragic and then, over time, begin to understand it as a blessing or as something that their child could overcome. While this is the case for some mothers, others show less of an emotional reaction but instead see disability as one of the natural conditions that occurs in human life. Hence, it must be noted that people do have different reactions.

Among many different emotions, one of the common responses observed by Alice and Karyn is the traumatic response they showed when they first faced their children's disabilities.

For example, it was clear that for Karyn facing her daughter's disability was a traumatic experience. As such, many parents begin their relationship with their children's disability with a certain level of shock, although the extent varies. Like Alice and Karyn, the extent of the shock they experience can be understood as trauma. Trauma, "as the majority of mental health professionals understand it, is the result of a deeply catastrophic event, like severe abuse or neglect. Such events are life altering, splintering a person's world into a 'before' and an 'after'."<sup>79</sup> Dr. Bessel van der Kolk, a trauma expert, in his book *The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma*, describes that traumatized people who disengage "simultaneously remember too little and too much."<sup>80</sup> Remembering all the details as a result of shock explains Karyn's trauma. Traumatic experience is most likely "to develop a host of physical and psychological conditions, from depression and anxiety to heart attacks, cancer, obesity, and stroke. The research is unequivocal: people with unresolved trauma get sicker and die younger."<sup>81</sup> Dr. Bessel van der Kolk said that traumatic experience "lodges itself in the body in diffuse ways." One way is that it affects the nervous system and evokes a fight-or-flight stress response.<sup>82</sup> Under the medical worldview, when we have a "problem," the way to fix is to use medicine. Fight-or-flight response is similarly observed in Alice and Karyn's attitudes toward disability. This in turn explains when mothers show strong resistance or shock, it is possible to infer the degree of the medical worldview in their minds.

---

<sup>79</sup> LePera, *How to Do the Work*, loc. 40 of 294, Kindle.

<sup>80</sup> Bessel vander Kolk, *The Body Keeps the Score*, quoted in LePera, *How to Do the Work*, loc. 40 of 294, Kindle.

<sup>81</sup> LePera, *How to Do the Work*, loc. 67 of 294, Kindle.

<sup>82</sup> LePera, *How to Do the Work*, loc. 43 of 294, Kindle.

After exploring emotional influence of the worldviews of an individual, then we can move on to explore more outside areas such as relationships, including family, friendship, work life and so on. The overarching question at this stage is to ask,

- “How does the worldview influence the person’s life, relationships, and losses?”<sup>83</sup>
- “How did the client come to know himself or herself in this problematic way?”<sup>84</sup>and
- What are “the patterns of its appearance in the careseeker’s life; its frequency, its intensity, the conditions of its waxing and waning?”<sup>85</sup>
- “How does ‘the problem’ affect your relationships in your family? How does it operate at school? How does it show up in your friendships? These types of questions help the person gain knowledge about how the problem is operating in their life.”<sup>86</sup>
- How do different perspectives influence the careseeker’s “different areas of life such as school, home, friendships, and work?”<sup>87</sup>

As a consequence of careseekers’ relationships with the worldview, careseekers can notice some gains and losses that have taken place. The questions to effectively explore these areas are

- “What kinds of losses were involved in the relationship with the problem? Was there “any resistance that the person has noticed regarding his or her response to the loss, and what all these events mean to the person telling the story?”<sup>88</sup>

---

<sup>83</sup> Madigan, *Narrative Therapy*, 77. I modified “problem” to “worldviews.”

<sup>84</sup> Madigan, *Narrative Therapy*, 74.

<sup>85</sup> Moschella, *Caring for Joy*, 257.

<sup>86</sup> Michael White, *Maps of Narrative Practice*, 43, quoted in Moschella, *Caring for Joy*, 258. Moschella writes, “Similar questions can be used to explore the effects of the problem on the person’s hopes and aspirations.”

<sup>87</sup> Michael White, *Maps of Narrative Practice*, 43, quoted in Moschella, *Caring for Joy*, 258.

<sup>88</sup> Madigan, *Narrative Therapy*, 74. “Tracing the negative influence the problem has had will allow for questions about the losses that have occurred in the person’s life while in relationship to the problem. For example, people in long-standing relationships with drugs, anorexia, anxiety, and so on, will always report losses concerning relationships with friends, school, jobs, hobbies, and family.” Madigan, *Narrative Therapy*, 77.



As the process of mapping the influences of the worldview, we have explored the worldview itself and its effect on mothers. Now it is time to explore mothers' responses toward these worldviews. Mothers must have their own ways of responding to their worldviews. Through exploring those responses, even if it is by a small gesture, caregivers can assist mothers in the discovery of their personal agency. Each mother responds to a given worldview/ problem in her own way. Gene Combs and Jill Freedman write that people's perception that they "have done nothing to stand against injustice or harm or that they are helpless to act can lead them to negative conclusions about their identities."<sup>89</sup> However, Combs and Freedman assert that this is not always the way that people are responding "even in the most limiting and abusive situations"<sup>90</sup> They said, regardless of how small the response are, to a small degree that may have gone unnoticed people are nonetheless at least responding. And recognizing these responses—although they didn't make noticeable changes in life, "contributes to a person having a sense of agency, of being an agent in his or her own life."<sup>91</sup> In addition, these responses usually become openings to preferred stories which is the major task of the next phase. Combs and Freedman added that these responses are the sign of people in some way attempting to separate from the problem by themselves.<sup>92</sup> Thus, the process of exploring how mothers respond to each operating worldview will give mothers and caregivers knowledge of their sense of agency at play. When exploring the response, rather than using the specific worldview, I encourage the caregiver to use the episodes or people that can exemplify specific worldviews.

- How did you respond to the X?
- What was it like to experience X?

---

<sup>89</sup> Combs and Freedman, "Narrative, Poststructuralism and Social Justice," 1042.

<sup>90</sup> Combs and Freedman, "Narrative, Poststructuralism and Social Justice," 1042.

<sup>91</sup> Combs and Freedman, "Narrative, Poststructuralism and Social Justice," 1042.

<sup>92</sup> Combs and Freedman, "Narrative, Poststructuralism and Social Justice," 1042.

These questions bring light to both careseeker and care giver not only in regard to the source of origin of the worldview but in regard to the nature of the careseeker's relationship. There is a good chance that some consistent patterns will emerge related to the worldviews. If it does, then, it would be helpful for the caregiver to remind the careseeker. The consistent pattern will be a clue for a careseeker about how she responds to a specific worldview or will point to her own perception of a specific worldview. The caregiver will likely notice the patterns that begin to emerge related to worldviews of disability. A careseeker can have a consistent relational pattern with specific worldviews including "the problem's appearances and tricks."<sup>93</sup> Then, caregiver share this discovery on the patterns with the careseeker because being aware of this pattern can significantly help careseeker to come up with "strategies to disempower the problem."<sup>94</sup>

The psychological effect of taking stock of the worldviews is to consider the worldviews as an independent entity that are likely to become infused/ entrenched in mothers' lives. While the careseeker and the caregiver explore together the history of the worldviews, what is intended here is for careseeker to realize that the worldview has its own history. It is not an essential factor in her life nor as "ubiquitous as it seems."<sup>95</sup> Any worldview is intrinsic or fundamental to any careseeker's life. Through exploring the effect, the careseeker begins to see that not all worldviews are powerful all the time, but some may be particularly prominent at particular moments or in particular situations. "These are hopeful realizations."<sup>96</sup> It helps the careseeker to begin to realize that they are not always encompassed by specific worldviews. "The careseeker remembers that there have been times when the problem as less powerful or even absent for a

---

<sup>93</sup> Moschella, *Caring for Joy*, 257.

<sup>94</sup> Moschella, *Caring for Joy*, 257.

<sup>95</sup> Moschella, *Caring for Joy*, 257.

<sup>96</sup> Moschella, *Caring for Joy*, 258.

while.”<sup>99</sup> Exploring mothers’ relationships with these various frameworks will enable mothers to see themselves from a wider perspective as those who are, in fact, outside of each framework. The result is they can see for themselves to what extent this particular framework has exerted an influence on their lives. Once mothers become able to map out whatever relationship they have established with each framework, they can learn that all frameworks make sense and yet none is absolutely right. Through this process, the dominant narrative of disability is disempowered; mothers can resist the influence of the dominant narrative of disability. At the same time, mothers’ sense of their own agency has grown. Why? Because the relational framework allows mothers to be at the center, as a subject who has relationships within different frameworks. Through the process mothers’ sense of agency is clarified, which makes it possible for mothers to have relationships with various frameworks. The premise for this is to envision mothers’ relationships from within these various perspectives. Mothers may have different kinds of relationships with different perspectives. This shift enables mothers to be at the center of their stories in relationship with different worldviews. Looking at the careseeker in this way, has an effect that is fundamentally similar to externalizing the problem as explained above. Through externalizing different perspectives on disability, the careseeker begins to see the whole person and her strength and wisdom in utilizing different perspectives of disability to adjust and to pave her child’s way in these multiple realities. What is happening is that it provides an opportunity for mothers to evaluate each perspective in light of their experiences. Understanding these different frameworks at play leads mothers to deconstruct these images and stop themselves from identifying with them. They will learn that they can be in each of these frameworks at different times or simultaneously—or they can be in none. The space is created for them to self-identify.

## Evaluation of Worldviews

The next move is to evaluate worldviews. This is not assessing the outcomes of therapy; it is to evaluate the influences of worldviews based on all the information gathered in the previous stages to ultimately decide with what kinds of worldviews mothers would like to develop relationships. So this is a stage at which to prepare this decision-making, and to develop preferred-stories in the next phase. To evaluate and prioritize according to the opinion of the careseeker. For this reason, the nature of the questions of therapists becomes more directly related to how each careseeker feels and thinks about worldviews, and herself in relationship or involved with certain worldviews whereas the previous stage of mapping influences was intended to guide the careseeker to recall and explore previous experiences. In this vein, it is more about seeking the meaning of experiences of the careseeker that so far she has explored together with the caregiver. I propose two therapeutic activities.

The first is to question the pros and cons of each worldview from the careseeker's perspective and experience. In the previous phase, we explored the influence of operating worldviews on the careseeker on a personal level as well as on different aspects of the careseeker's life, such as family, personal growth, workplace, and relationship with her child. Now is the time to evaluate those influences through pros and cons and the benefits and costs to the careseeker. Moschella points out that "in the fuller context, sometimes a problem has both costs and benefits."<sup>97</sup> The same worldview can have pros in one aspect and cons in another aspect. The pros and cons of each perspective may differ according to areas of each careseeker's life. For example, while the medical perspective allows pragmatic benefits, it can also be detrimental when it comes to mothers' relationships with their children. The task of a therapist

---

<sup>97</sup> Moschella, *Caring for Joy*, 258.

and a careseeker, then, becomes not to drop certain worldviews entirely but to understand their costs and benefits and redefine a mother's relationship in a way that she can wisely navigate both streams.<sup>98</sup> This process can help mothers to improve their sense of agency.<sup>99</sup> Example questions are:

- “How do you feel about these developments?”<sup>100</sup>
- “Where do you stand on these outcomes?”<sup>101</sup>

The second is to explore the internalized messages that the careseeker receives through each worldview and to take a chance to examine whether what these internalized messages of the worldviews *mean* to mothers. By this time, it becomes possible and important to begin to recognize internalized messages mothers receive or identities mothers are given via different perspectives. As noted in the previous chapter, each worldview has its own value. However, the value and meaning that careseekers understand as they interact with different worldviews may vary. People's distinctive life experiences and circumstances will shape the message more particularly. Seeking an internalized message of different worldviews also has an educational effect in that mothers now gain the skill set needed to question internal messages of narratives, dominant cultural ideas, and learn to explore their own way to respond to them. It can at least help mothers delay the influence of cultures by interfering through awareness.

Through the processes of mapping influence and the evaluation, people begin to realize how they have joined in supporting their problems and “begin to see themselves as authors, or at

---

<sup>98</sup> Moschella, *Caring for Joy*, 258.

<sup>99</sup> Moschella, *Caring for Joy*, 258.

<sup>100</sup> Moschella, *Caring for Joy*, 258.

<sup>101</sup> Moschella, *Caring for Joy*, 258.

least coauthors, of their own stories.”<sup>102</sup> “They can then move toward a greater sense of agency in their lives as the primary author of the story to be told and lived through.”<sup>103</sup>

At this point, with all the information that has been gathered, mothers gain clarity on the dynamics of worldviews in their lives; it means they are closer to gaining their own voices. With the data collected between careseeker and therapist, the careseeker is ready to re-author her own story with intention.

### **Developing Preferred Stories: Re-Membering**

In the previous section, we went through a process of mapping the influence of the worldviews and evaluating each different worldview’s influence in a careseeker’s life. The underlying goal of these activities was to separate the worldviews from the person. According to Gene Combs and Jill Freedman, once there is an externalization, “people are in a better position to make choices about their preferred directions in life.”<sup>104</sup> Now that caregiver and careseeker both gain sufficient knowledge about the worldviews and their influences on the careseeker, these sources will be used for a careseeker to decide for herself which worldviews are to be at play and to what degree in her life, fully employing practical wisdom with intention. Furthermore, they will also have an opportunity to explore what kinds of meaning the notion of disability has for themselves among many different meanings of disability. This we call “weave[ing] the new preferred story into their life narrative”<sup>105</sup> which will be the major task of the last stage. Through this process, the careseeker will feel her agency fully activated by engaging in re-authoring her story. Re-authoring not only assists the careseeker to gain and use

---

<sup>102</sup> Madigan, *Narrative Therapy*, 77.

<sup>103</sup> Madigan, *Narrative Therapy*, 77.

<sup>104</sup> Combs and Freedman, “Narrative, Poststructuralism, and Social Justice,” 1053.

<sup>105</sup> Moschella, *Caring for Joy*, 262.

her voice but also supports her to make a choice on which worldviews she will use. These choices she made in developing preferred stories will reflect her authentic truth, in a way that “restorying is taking back into oneself”<sup>106</sup> into her story as a protagonist. The new stories will begin to edge out the old narrative<sup>107</sup> which mostly involved being occupied in multiple worldviews without necessarily being aware of her agency. The caregiver in this stage supports the choices of the careseeker in developing preferred life choices 113 and become “an audience, bearing witness to the new story that is being told and lived.”<sup>108</sup>

As part of the process of weaving a new narrative, I bring and modify one of the White’s therapeutic skills of “re-membering.” White writes,

This definition of re-membering evokes the image of a person’s life and identity as an association or a club. The membership of this association of life is made up of the significant figures of a person’s history, as well as the identities of the person’s present circumstances, whose voices are influential with regard to how the person constructs his or her own identity. Re-membering conversations provide an opportunity for people to engage in a revision of the membership of their associations of life, affording an opening for the reconstruction of their identity.<sup>114</sup>

Re-membering conversation is based on the idea that one’s sense of identity is constructed in relation to a person, community or in specific context, in White’s term, “association of life.”<sup>109</sup> This opposes a notion of self as having a core self. The implication of this kind of understanding of identity is hopeful because if there is only one absolute, essential self and that self is damaged in some senses, then it must be difficult to recover or reclaim that self; because there is one core self. However, when conceiving our identities born, reinforced, and sustained in different contexts, more specifically, in the context of relationships, we are not

---

<sup>106</sup> Moschella, *Caring for Joy*, 262.

<sup>107</sup> Moschella, *Caring for Joy*, 262.

<sup>108</sup> Moschella, *Caring for Joy*, 262.

<sup>109</sup> Michael White, *Maps of Narrative Practice*, 115.

subject to finding an essential self. Instead, human agency is brought forth as now in our hands to amend, create and develop our preferred identity.

As such, re-membering assists people to “upgrade some memberships and to downgrade others; to honor some memberships and to revoke others; to grant authority to some voices in regard to matters of one’s personal identity, and to disqualify other voices with regard to this.”<sup>110</sup> The process of re-membering is “purposive reengagements with the history of one’s relationship”<sup>111</sup> and I argue that this rearrangement can take place with the worldviews.

In modifying White’s re-membering practice, I also think that John Patton’s notion of “re-membering” is closely relevant in that it is used in the context of community. My use of re-membering encompasses both White’s point of rekindling the undervalued but important and meaningful relational self and Patton’s focus on being remembered as part of community as I set forth in the notion of ‘community of worldview’ in chapter 5. In this dissertation’s context, mothers will “re-member” their relational experiences dynamics within various communities of worldviews.

This enables us to see the mothers’ part of their conception of disability and sense of identity constructed in relation to their association with the worldview. Ultimately, it activates mothers’ agency of being in full command of orchestrating various worldviews. This therapeutic conversation also acknowledges mothers and provides the experience of taking charge of the worldviews that they can use in their real lives. Now that we have come to identify and evaluate various operating worldviews in mothers’ narratives, this is the time when mothers will be able to “call” what kinds of membership they want to upgrade or degrade.

- What is your role when you are in X

---

<sup>110</sup> White, *Maps of Narrative Practice*, 116.

<sup>111</sup> White, *Maps of Narrative Practice*, 117.



- Do you have any understanding how you contributed
- What is your understanding of yourself when
- What is your guess

It can take “time to live into the new narrative,” Moschella points out, “with all of its practical and interpersonal and emotional challenges.”<sup>112</sup> The transformation of one’s story is often symbolized as a journey.<sup>113</sup> This is the case, especially in the case of a change of narrative or self-identity—or “insights into a new way of thinking and being”<sup>114</sup> in a way that is congruent with the story they prefer. The changes that careseekers wish to make may require developing practical, interpersonal, or emotional skills or make it necessary to attain financial stability. Having a conversation about what things might be important to remember when going back to life with a careseeker can be helpful; it provides opportunity for a careseeker to imagine being a head of the life-story she wants to live into and set her own agenda and points to remember for herself.

For these reasons, this migration of identity, most of the time, must go through a space called ‘betwixt and between’ also a “transitional space,” notion from Winnicott as I mentioned in the beginning of this chapter. In this space, the careseeker can experience confusion and disorientation in the face of a new reality and with the attempt to live a preferred narrative. This therapeutic space is exactly meant to explore those uncertainties. This is a time when careseeker feel the urge to go back to their former, comfortable way of life.<sup>115</sup> Some people may decide to return to the old story and their former identity.<sup>116</sup> Thus, it becomes important for therapists to

---

<sup>112</sup> Moschella, *Caring for Joy*, 263.

<sup>113</sup> Moschella, *Caring for Joy*, 263. Moschella refers the reader to David Denborough, *Retelling the Stories of Our Lives*, especially chap. 5, “Life as a Journey: Migrations of Identity,” 121–43.

<sup>114</sup> David Denborough, *Retelling the Stories of Our Lives: Everyday Narrative Therapy to Draw Inspiration and Transform Experience*, 123, quoted in Moschella, *Caring for Joy*, 262.

<sup>115</sup> Moschella, *Caring for Joy*, 263.

<sup>116</sup> Moschella, *Caring for Joy*, 263.

support, walk together with the careseeker into the process of “migration” by encouraging the careseeker to remember “their progress over time, including the pattern of ‘waves and troughs’ that can be expected to accompany” the journey.<sup>117</sup> Psychologically, Neuger explains that gaining a voice is, in fact, arriving at “a new awareness—a transforming awareness—for the sake of empowering the self.”<sup>118</sup> That is, developing new stories and identities are, to some degree, creating a new hermeneutics of oneself. This process itself also enables people to imagine the possibility of transformation and moreover to realize that transformation is possible and to accept that one’s life story can also be changed in a way that is life-giving and truthful—such that their stories can be congruent with their “values, intentions, and beliefs.”<sup>119</sup>

This re-membering can be an expression of resistance toward the dominant culture that has been toxic to careseekers because as careseekers begin to construct and align their lives, they disempower their tendency to unwittingly accept dominant cultural values they used to accept.<sup>120</sup> It is their way “to marshal the power of social, cultural, and institutional support for individuals’ and families’ preferred interpretations of their identity and history.”<sup>121</sup> Theologically, re-authoring is “to engage in authentic response to God and to others. Re-authoring helps people become able to seek and follow their vocations without the chains of falsehoods about the self, about their places in the world, and about their gifts and grace.”<sup>122</sup>

---

<sup>117</sup> Denborough, *Retelling the Stories of Our Lives*, 123, quoted in Moschella, *Caring for Joy*, 263.

<sup>118</sup> Neuger, *Counseling Women*, 137.

<sup>119</sup> Moschella, *Caring for Joy*, 251.

<sup>120</sup> Moschella, *Caring for Joy*, 251.

<sup>121</sup> Moschella, *Caring for Joy*, 264.

<sup>122</sup> Neuger, *Counseling Women*, 137.

## Epilogue

So far, I have built the argument that any understanding of disability is associated with one's faith as it is part of larger systematic and wholesome worldviews. Then, how do I understand disability? More precisely, how do I *believe* what disability is? I mentioned in the introduction that I see disability as something that simply transpires. I personally do not try to imbue disability with any meaning. Rather, to put it more correctly, I do my best to be aware of conceptions or meaning that I project to disability. And I try to see those notions as mine. In this way, I am trying to empty the meaning that I have so naturally learned to associate with disability. Still, if I am being asked What is my own theological understanding of disability? I must say yes. I see disability as a different bodily embodiment. Equal soul or spirit but different kinds of representation in this world or in the reality we live in. The notion of spirituality requires us to engage with imagination. I return to the religious notion of "spirituality." I think it is inevitable that I return to the concept of spirituality. I see there is something that scientific or psychological language cannot capture in their effort to make sense of disability, furthermore, some of the human phenomenon. Perhaps this is the reason why I cannot help but be a theologian. To come to this point, I must take the journey to reach an understanding of disability in the most theologically sound way. So, I must say that the theological meaning I have found may not work for other people, for I now believe that only when one takes the journey, can one find the meaning that suits her.

## Appendix A

### Various Communities and Their Worldviews

In this appendix, I introduce various communities and their worldviews of disability.

#### The Medical Worldview of Disability: Disability as a Disease

This worldview is also called a biomedical worldview as it views a human from the biomedical perspective. The world of the medical understanding is a world of health, function (ability) and competency. The objective of this worldview is to have a body that is functioning, competent and experiencing the least possible pain. The human body is the primary object of medical professionals' intervention.<sup>1</sup> Thus, the medical worldview inevitably 1) has a positive view of a body that doesn't need a cure or treatment or is a cured body and 2) has a negative view of what caused the body to be in need of cure. Clearly, the medical worldview has a dichotomous dimension in its understanding of the human condition.

Disability is “a deficit” or “a failure of a bodily system” “and as such is inherently abnormal and pathological.”<sup>2</sup> It refers to that which has “deviated from what is normal.”<sup>3</sup> The terms considered pejorative when directed toward people with disabilities—terms such as “‘invalid,’ ‘cripple,’ ‘spastic,’ ‘handicapped,’ and ‘retarded’—are all derived from the medical field.”<sup>4</sup>

---

<sup>1</sup> Jon Tilburt and Gail Geller, “Viewpoint: The Importance of Worldviews for Medical Education,” *Academic Medicine: Journal of the Association of Medical Colleges* 82, no. 8 (2007 August): 819–22, <https://pubmed.ncbi.nlm.nih.gov/17762266/>.

<sup>2</sup> Retief and Letsosa, “Models of Disability,” 2–3.

<sup>3</sup> Retief and Letsosa, “Models of Disability,” 2–3.

<sup>4</sup> Retief and Letsosa, “Models of Disability,” 2–3.

Because a medical problem resides within an individual, the medical worldview tends to disregard the possible contextual or environmental issues that might influence a person's functional abilities.<sup>5</sup> "Accordingly, the medical worldview tends to regard the person with disability as the one who needs to change or be fixed, not the conditions that might be contributing to the person's disability."<sup>6</sup> This kind of diagnosis often leads to a treatment of "people as problems to be solved, often failing to take into account the various aspects related to the person's life as a whole."<sup>7</sup> This is a major and serious point of criticism from a theological or humanitarian perspective. Cure and treatment, the main task of the medical world, take place with this very specific understanding of the human condition. "The goals of intervention are cure, amelioration of the physical condition to the greatest extent possible, and rehabilitation (i.e., the adjustment of the person with the disability to the condition and to the environment)."<sup>8</sup> Based on this understanding of the human body, the aim is to change and influence the status of what is considered dysfunctional to make it functional. In other words, intervention aims to eliminate disabilities in our body and improve abilities. This is the reason why the medical understanding of disability is regarded as being deeply connected to the 'personal tragedy' worldview, because of its interpretation as "fundamentally a deficit, a negative condition."<sup>9</sup>

From Andrew Lester's perspective, the hoped-for ideal human condition presented in the medical worldview is inevitably a finite hope which cannot avoid some level of despair because of the potentially dysfunctional future story. Their hope is heavily conditioned by their reality.

---

<sup>5</sup> Retief and Letsosa, "Models of Disability," 2–3.

<sup>6</sup> Retief and Letsosa, "Models of Disability," 2–3.

<sup>7</sup> Retief and Letsosa, "Models of Disability," 2–3.

<sup>8</sup> Retief and Letsosa, "Models of Disability," 2–3.

<sup>9</sup> Retief and Letsosa, "Models of Disability," 2–3.

Then, how does the medical worldview assess the improvement? In the medical world, “improvement is measured with objectively quantifiable instruments.”<sup>10</sup> To undertake the treatment process, medical professionals use their intellect and apply it to biomedical facts that “are external, material, objective realities that can be measured.” The ultimate goal of these activities is to improve the bodily function that has become ill or disabled.<sup>11</sup>

The professionals’ medical perspective toward ‘facts’ reflects the legacy of Descartes, who separated “the nonmaterial mind” from “the material body.”<sup>12</sup> This dual mind–body model has facilitated significant practical advances in medical technology over the last 150 years by allowing scientists and physicians to manipulate the physical world and thereby intervene in disease processes. Tilburt and Geller point out that despite many attempts to reveal the limitations of this duality and search for alternative understanding, this dualistic biomedical premise still strongly persists until these days.<sup>13</sup>

Furthermore, Tilburt and Geller assert that these kinds of “epistemological assumptions” in the medical field are limited and for good reasons.<sup>14</sup> In producing medical knowledge, the field chooses to use certain methods. For instance, “mechanistic knowledge about molecular and cellular physiology are considered the soundest sources of knowledge.”<sup>15</sup> These bodies of knowledge are likely to be produced under “highly controlled human experiments, such as randomized controlled trials.”<sup>16</sup> Only the knowledge generated with this given specific method, is “considered a sound source of “objective” knowledge”<sup>17</sup> It is from this perspective that the

---

<sup>10</sup> Tilburt and Geller, “Viewpoint.”

<sup>11</sup> Tilburt and Geller, “Viewpoint.”

<sup>12</sup> Tilburt and Geller, “Viewpoint.”

<sup>13</sup> Tilburt and Geller, “Viewpoint.”

<sup>14</sup> Tilburt and Geller, “Viewpoint.”

<sup>15</sup> Tilburt and Geller, “Viewpoint.”

<sup>16</sup> Tilburt and Geller, “Viewpoint.”

<sup>17</sup> Tilburt and Geller, “Viewpoint.”

social and behavioral sciences are considered to be “softer sciences (i.e., more subjective.) and less reliable sources of knowledge.”<sup>18</sup> Tilburt and Geller saw these assumptions about knowledge, and the character of medical perspective as being limited and they encouraged others to incorporate other humanistic-oriented perspectives into medical education, although it is like “fighting an uphill battle against the cultural mindset of biomedicine.”<sup>19</sup>

In this regard, we can see that the medical worldview assume that there is an obvious power structure between what is considered to be objective knowledge and what is less objective knowledge. In Foucault’s words, “[T]his action emerges from discourses that are produced and given the status of ‘science.’”<sup>20</sup> The more the action follows what is considered to be an authoritative method, the more ‘power’ can be exercised in generating medical knowledge. In this regard, power resides in ‘facts’ and in the discipline of science.

Exemplary practices involve objectifying patients. First, “Persons with disabilities are expected to avail themselves of the variety of services offered to them and to spend time in the role of patient or learner being helped by trained professionals.”<sup>21</sup> Second, disability is identified as a scientific classification. It is exactly in regard to this ‘scientific classification’ that Michael Foucault offers his criticism. From Foucault’s perspective, this ‘scientific classification’ based on what are considered facts is one mode of turning human beings into objectified subjects.<sup>22</sup> When the human body becomes an object to be classified according to the biomedical standard, the scientific classification becomes a “practice of making the body a thing.”<sup>23</sup> An example he

---

<sup>18</sup> Tilburt and Geller, “Viewpoint.”

<sup>19</sup> Tilburt and Geller, “Viewpoint,”

<sup>20</sup> Michel Foucault, quoted in Madigan, *Narrative Therapy*, 29.

<sup>21</sup> Retief and Letsosa, “Models of Disability,” 3.

<sup>22</sup> Madigan, *Narrative Therapy*, 29.

<sup>23</sup> Madigan, *Narrative Therapy*, 29.

identified is the use of psychiatric diagnostic testing based on the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*.<sup>24</sup>

The agents that employ these practices are mostly in the fields of medicine, insurance, corporations and education.<sup>25</sup> They documented people's lives through the invention of files and these files "enabled individuals to be 'captured' and fixed in time through writing, and this action could be used to facilitate the gathering of statistics and the fixing of norms."<sup>26</sup> Madigan, adopting the perspective of Foucault, asserts that this file "could also be used as an instrument to promote the construction of unitary and global knowledges about people. The turning of real lives into documented written files is viewed by Foucault as a mechanism of social control."<sup>27</sup>

Similarly, Madigan argues that broadly labeling as normal or abnormal, and specifically naming with a diagnosis, has become an accepted cultural phenomenon. "Storylines for *DSM-5* disorders might seem far-fetched until one checks out diagnosis-focused blogs on the web, watches confessional TV shows, or turns to the self-help literature."<sup>28</sup> Madigan quotes Eva Illouz, a sociology professor at Tel Aviv University, who "saw the matrix of mainstream individual pathologizing as the way to make sense of experience and oneself as central to participating in everyday cultural interaction."<sup>29</sup> Similar point has made by a psychologist Svend Brinkmann who coined the term 'diagnostic cultures.'<sup>30</sup> That is, "*DSM* diagnoses, such as ADHD or depression, are becoming central to one's identity. In other words, diagnosis-related

---

<sup>24</sup> Madigan, *Narrative Therapy*, 29.

<sup>25</sup> Madigan, *Narrative Therapy*, 30.

<sup>26</sup> Madigan, *Narrative Therapy*, 30.

<sup>27</sup> Madigan, *Narrative Therapy*, 30.

<sup>28</sup> Madigan, *Narrative Therapy*, 41.

<sup>29</sup> Madigan, *Narrative Therapy*, 41.

<sup>30</sup> Madigan, *Narrative Therapy*, 41.



stories become interwoven with everyday life, often in ways that foretell or perhaps foreclose on life's possibilities."<sup>31</sup>

Even apart from medical and clinical agencies, most of the public sectors that include education, social security, the law are based on the aforementioned system of medicine. For example, schools will exempt absences if they are for medical reasons, which is verified by a document produced by the medical authority.

### **The Moral and/or Religious Worldview: Disability as an Act of God**

The moral/religious worldview of disability is the oldest understanding of disability and is "found in a number of religious traditions, including the Judeo-Christian tradition."<sup>32</sup> In this world, the agency of God, or theologically speaking, the sovereignty of God is a primary motivation of the world, including what is happening on an individual level. People with this moral and theological mindset most likely feel powerless in the face of God's action. Bringing in the context of disability, God is the Being who has decided who will suffer what kinds of disability. Disability becomes a tool for God's involvement with people.

God confers disability on people either as a deserved punishment from God or as the free action of an Ultimate Being. It is a punishment of the religiously sinful or morally wrongful action done by an individual or an individual's parent and/or ancestor. This worldview is considered "no longer as prevalent as it was in premodern times";<sup>33</sup> however, "the basic philosophy underlying the model[worldview] is still frequently encountered in the way people reason when confronted with illness or disability."<sup>34</sup>

---

<sup>31</sup> Madigan, *Narrative Therapy*, 41.

<sup>32</sup> Retief and Letsosa, "Models of Disability," 2.

<sup>33</sup> Retief and Letsosa, "Models of Disability," 2.

<sup>34</sup> Retief and Letsosa, "Models of Disability," 2.

John Swinton understands this worldview as the equivalent of the medical understanding of disability in that it locates disability purely within the individual.<sup>35</sup> Within this understanding, Swinton points out that ministers who undertake the healing ministry assume a role similar to that of the medical professionals in the effort to return “the individual to as close an approximation of the accepted norm as possible.”<sup>36</sup> I agree with Swinton’s point that this moral/religious worldview correlates with the medical worldview. It is because the observed effect is similar to the finite hope that this worldview yields. Change must be initiated by an external factor, or by God, the ultimate being; human persons are automatically subjugated to the will of God.

Psychologically, what I see as the essence of this worldview is the element of fear this worldview embodies and represents. It evokes innate feelings of fear or guilt. It largely points toward people’s fear in that it stresses the vulnerable human reality without agency in the face of disability. It also evokes guilt, primarily within parents, who fear they did something wrong and that they are not good parents which caused the disability of their children.

In these more informed times, there are fewer communities that hold to this worldview and, in my observation, it is not popular enough to be claimed in the public realm. A great deal of theological work has been done to correct this traditional understanding by exemplary theologians John Swinton, Kathy Black and others. However, as a researcher who has done research on parents and mothers of children with disabilities, I know this moral/religious worldview is still alive and perhaps because it is given less recognition those who have this sense of guilt, even in this lesser degree, have little access to psychological and emotional treatment that can resolve this misperception. The guilt is not logical, but it is alive and in need of

---

<sup>35</sup> Swinton, “Disability, Ableism, and Disablism,” 444.

<sup>36</sup> Swinton, “Disability, Ableism, and Disablism,” 444.

psychological and emotional treatment. I have seen many mothers who were processing their sense of guilt and fear in relation to their children's disability.

### **The Social Worldview: Disability as a Socially Constructed Phenomenon**

The social worldview locates itself in an exactly oppositional position with both a moral/religious worldview and the medical worldview by relocating the disability from an individual to a social context. The social worldview of disability is known to be “inspired by the activism of the British disability movement in the 1960s and the 1970s,” “in reaction to the limitations of the medical model[worldview] of disability.”<sup>37</sup> The social worldview of disability strongly resists the medical worldview of disability, and its strong intention is to undo the harm done by the medical worldview. The term ‘social model of disability’ was coined by Mike Oliver, himself a disabled activist and lecturer.<sup>38</sup>

Fundamental to the assumption of “the social model[worldview] of disability is the notion that disability is ultimately a socially constructed phenomenon.”<sup>39</sup> The key concepts associated with the social worldview of disability are ‘constructiveness’ and ‘deconstruction.’ That is, having a critical perspective is most importantly considered. It encourages us *not* to take a thing or a person as initially seen or called, but to rigorously and critically question why this is what it is said to be. Through the process of questioning, one learns to pay attention to the politics and power dynamics behind claims. For example, when I was taking a summer course at University of California in Los Angeles (UCLA), an Introduction to Disability Studies, the class activity on the first day was to illustrate the constructivism that can be applied to daily lives. The

---

<sup>37</sup> Retief and Letsosa, “Models of Disability,” 3.

<sup>38</sup> Retief and Letsosa, “Models of Disability,” 3.

<sup>39</sup> Retief and Letsosa, “Models of Disability,” 3.

instructor asked all the students to stand, and he had us stand in a line according to height, from the shortest to the tallest. When we were in line, the instructor pointed out that those in the middle were likely to be standard in our daily lives, including sizes of our clothing, construction of buildings, and such. The message was clear: The majority becomes the standard because they are the majority. When a certain group of people are called ‘normal,’ those who are in the front or back of the line are more likely to be considered ‘abnormal’ in comparison.

Unlike the medical worldview which essentializes the meaning of disability, the social worldview does not take this essentialist approach. There is no essential meaning in the term disability, rather it indicates an experience that is especially associated with mistreatment and injustice. According to the *Fundamental Principles of Disability* (1976), a manifesto document written by authors of Union of the Physically Impaired Against Segregation (UPIAS)—which is considered one of the most important documents in the development of this approach—defines disability as follows:

[D]isability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people.<sup>40</sup>

From this definition we can see that disability is understood as “a social experience that is shaped and formed by the particular context in which a person’s perceived difference is experienced.”<sup>41</sup> This approach reflects people’s understanding of disability, and it is in this context that Deborah Creamer argues that the study of disability is in fact the study of common assumptions on economics, politics, and so on.

---

<sup>40</sup> Union of the Physically Impaired against Segregation, *Fundamental Principles of Disability* (London: Author, 1976), 3, quoted in Retief and Letsosa, “Models of Disability,” 3.

<sup>41</sup> Swinton, “Disability, Ableism, and Disablism,” 444.

Because the context decides whether this person is normal or abnormal, consequently, from this perspective, “it is society ‘which disables people with impairments, and therefore any meaningful solution must be directed at societal change rather than individual adjustment and rehabilitation.’”<sup>42</sup> Logically, activism consists of the essential element in this approach. People who subscribe to the social worldview do engage with social activism, or at least believe that that activism is the right thing to do. This approach has played a critical role in eliciting the legislation of disability law and shaping social policy.<sup>43</sup>

Then, what about the human condition? If what we generally consider ‘disability’ is constructed to be a notion about a social condition, how do we understand how apparent functional limits and differences are represented? This is where the social worldview theorists brought the notion of ‘impairment.’ The notions of “disability” and “impairment” are clearly distinguished in the social worldview. Impairments such as blindness, deafness and so forth are not necessarily ‘disabling,’ as “it is the negative reactions of society to these impairments that is disabling.”<sup>44</sup>

Because what defines disability is by outside factors—such as environment or society—this perspective has the tendency to see people with disabilities as scapegoats of the social system that has been structured by a dominant power. From the social worldview alone, there is a possibility that people with disabilities can be seen as lacking in agency or as scapegoats of the dominant oppressive society. This tendency can be strengthening, especially when an individual attempts to understand herself while engaging in practices that involve the social worldview

---

<sup>42</sup> Barnes, C., Mercer, G. & Shakespeare, T., 2010, ‘The social model of disability’, in A. Giddens & P. Sutton (eds.), *Sociology: Introductory readings*, 3rd ed., pp. 161–166, Polity Press, Cambridge, 163. Quoted in Retief and Letsosa, “Models of Disability,” 3.

<sup>43</sup> Retief and Letsosa, “Models of Disability,” 4.

<sup>44</sup> Swinton, “Disability, Ableism, and Disablism,” 444.

because when this worldview critiques the social system as the origin of oppression, it inevitably implies acknowledgement of the dominant social system's power that is imposed on individuals.<sup>45</sup>

While one's impairment can be an obstacle for a person to exercise one's full ability, impairment should not be a reason for a person to be discriminated against. This point logically leads to the human rights worldview and to some degree relates to the identity worldview. It can be understood to relate to the identity worldview in that, in this worldview, whether a human person has impairment or not, they are all valued equally, and disabilities or limitations are understood as mere 'differences' as on the identity worldview. It leads to the human rights worldview because the social worldview can hardly stand alone without the human rights worldview, in that the social worldview has the strength only to critique the status quo, but not to establish an alternative worldview. The human rights worldview provides the practical theoretical framework within which people with disabilities can establish their claim to legal and civil rights. For the social worldview, strength lies in their ability to deconstruct the status quo and significant weakness lies in their inability to construct a new standard.

Ironically, in this world, because weight is inevitably given to the 'experience of the disabled,' it is impossible to avoid criticism that this has led to an exclusivity for those who aren't clearly identified as disabled, those who are not disabled, or those who are so seriously disabled that they cannot join the activism.<sup>46</sup> It is because the approach that disability needs to be defined based on "people's experience as an oppressed minority group" cannot embrace "the experiences of people who are not and cannot be a part of any politically active group, such as

---

<sup>45</sup> This was also pointed out by Nancy Eiesland.

<sup>46</sup> Swinton, "Disability, Ableism, and Disablism," 445.

those with profound intellectual disabilities or advanced dementia.”<sup>47</sup> For this reason, Swinton points out that “minority group models[worldviews] can end up being exclusive rather than inclusive. My point here is not that these approaches are wrong. They are, however, inadequate.”<sup>48</sup>

Nonetheless, the social worldview of disability has been one of the most popular among theologians. Theologians, starting from Nancy Eiesland, have employed the social worldview approach in theological reflection to analyze and mostly critique traditional theologies that have been used to oppress and undervalue people with disabilities in church settings. In Swinton’s words, “this movement from the personal to the social raises a hermeneutic of suspicion with regard to the ways in which the church has interpreted disability.”<sup>49</sup> Thereby, theologians such as Nancy Eiesland and others began to revise and reconstruct theology and practice.

### **The Identity or Affirmation Worldview of Disability (or the Affirmation Worldview)**

This approach expresses a resistance to understanding disability in a negative light. Metaphors of ultimate reality of the identity worldview of disability is that ‘every human being has different identity,’ identity including disabilities, and ‘the difference of identities is good.’ A similar campaign can be found in the slogan “Black is beautiful.” The primary distinctiveness of this approach is to imbue a new and positive meaning to disability that has generally been considered negative. According to Brewer et al., this approach shares the social model’s [worldview’s] understanding that the experience of disability is socially constructed but differs to

---

<sup>47</sup> Swinton, “Disability, Ableism, and Disablism,” 444.

<sup>48</sup> Swinton, “Disability, Ableism, and Disablism,” 445.

<sup>49</sup> Swinton, “Disability, Ableism, and Disablism,” 444.

the extent that it “claims disability as a positive identity.”<sup>50</sup> Retief and Letsosa note that “The identity worldview has influenced many in the disability community, inspiring people with disability to adopt a positive self-image that celebrates ‘disability pride.’”<sup>51</sup>

The positive identity becomes “a marker of membership in a minority identity, much like gender or race,”<sup>52</sup> as this approach is concerned to “have created a recognizable minority group called ‘people with disabilities.’”<sup>53</sup> The employment of the identity worldview can motivate “people with disabilities to belong to a campaigning group, which aids in the development of a collective identity.”<sup>54</sup>

When introducing or arguing for this approach, one of the exemplary groups that is often used is the deaf community. According to Hill and Goldstein, the deaf community offers a positive way to understand the experience of being deaf, “there is affirmative value—not just ordinariness—to being people with disabilities. People with disabilities . . . contribute . . . an incomparable ability to solve problems and be innovative, a positive attitude under persistent adversity, and an appreciation of difference.”<sup>55</sup> (I consider this a theological version of the identity worldview, which also uses this example to emphasize the positivity of disabilities.)

Besides, I think this approach shows some degree of the acknowledgement of the medical worldview by accepting the impairment—except that it imbues it with positive meaning and value, unlike the medical understanding where its meaning is negative. One of the limitations of the identity worldview is that “the identity model [worldview] negates the struggle for

---

<sup>50</sup> E. Brewer et al., “Introduction, Background, and History,” in *Arts and Humanities*, ed. B. Brueggemann (Thousand Oaks, CA: Sage, 2012), quoted in Retief and Letsosa, “Models of Disability,” 5.

<sup>51</sup> Retief and Letsosa, “Models of Disability,” 5.

<sup>52</sup> Retief and Letsosa, “Models of Disability,” 6.

<sup>53</sup> Retief and Letsosa, “Models of Disability,” 5.

<sup>54</sup> Retief and Letsosa, “Models of Disability,” 5.

<sup>55</sup> Hill and Goldstein, “The ADA, Disability, and Identity,” *JAMA* 313, no. 22 (2015), 2228 quoted in Lawrence O. Gostin, “The Americans with Disabilities Act at 25: The Highest Expression of American Values,” *JAMA* 313, no. 22 (2015), 2232.



redistribution, failing to pay sufficient attention to the reality of economic inequality faced by people with disabilities.”<sup>56</sup> That is, it is less pragmatic in the reality of the lives of people with disabilities.

There is a theologically corresponding worldview with this identity approach, that attributes disability to a fundamental aspect of the human person which I will introduce in the next section.

### **The Theological Identity Worldview**

‘Theological Identity Worldview’ is a term I coined in order to differentiate the theological version from the identity worldview of disability. While the identity worldview considers the characteristics of disability as not necessarily in regard to the human and God relationship, the theological identity worldview shows a tendency to attribute the characteristics of disability to God or to the human in relation to God. That is, this approach uses a method that is similar to the identity worldview in that it imbues disability with a positive meaning and, in fact, it baptizes the disability with theological meaning. Theologically, it is interpreted usually in two ways. First by universalizing it into fundamental humanness, that is to experience disability is to be human. Second, attributing disabilities to God, that is, disabilities are part of God’s nature; God embodies the disabilities. While this method, whether one appeals to God’s nature or human nature, both theories tend to evoke fundamentals of human beings and they usually result in weakening the boundary drawn between people with disabilities and people without disabilities. This effect is similar to that observed with the identity worldview.

---

<sup>56</sup> Retief and Letsosa, “Models of Disability,” 5.

## Disability as Part of Being Human

In this worldview, the meaning of disability is expanded, and it functions as a way to delineate what it means to be human. This understanding has been generated by theologians or Christian ethicists with a specific intention: to ameliorate the prejudice toward disability that regards them as ‘others’ and to be able to accept disability as part of the fundamental nature of human beings. In this world, unlike other worldviews, disability becomes one of the characteristics of a human being and functions as just one of the many things that differentiate people. And precisely because of this—to put it roughly—meaning-making and generalization, this worldview has been criticized as being non-pragmatic or less practical in its result or implication.

The prime examples are developed by Deborah Creamer and Tom Reynold. Creamer develops a limit worldview in 2019. “In this model [worldview], disability is best understood with reference to the notions of embodiment and ‘limitness.’ This ‘limitness’ is experienced by all human beings “to varying degrees during all the phases of our lives.”<sup>57</sup> Therefore, it is, in fact, “a common, indeed quite unsurprising, aspect of being human.”<sup>58</sup> When Creamer developed the limit worldview, she knew the limits of the social worldview, especially in regard to its exclusiveness. Creamer was clear that her limit worldview departed from the social worldview which has as its primary focus the social context and the shared experience of oppression. Her proposal of the limit worldview was developed partly to complement this exclusivity and to overcome it by expanding the meaning of disability as “an unsurprising aspect of being

---

<sup>57</sup> Retief and Letsosa, “Models of Disability,” 7.

<sup>58</sup> Creamer, *Disability and Christian Theology*, 31.

human.”<sup>59</sup> This “guards against overdetermining the situation of people with disabilities vis-à-vis the wider population.”<sup>60</sup>

Creamer’s limit worldview also attempts to distract the medical worldview’s equation of disability to the problem by asserting that limit need not be equated with “problems.”<sup>61</sup> In doing so, Creamer distinguishes the notion of limits and limitations. To Creamer, limits are more of general predicament of human beings. However, when limitation is given negativized ‘limits,’ it implies a negative value judgement is placed upon limits. Creamer posits that “our limits need not (and perhaps ought not) be seen as negative” but as “an important part of being human.”<sup>62</sup> Limits, for Creamer, of course can be inconvenient and prevent us from doing some things—such as being blind will prevent us from driving—but they are neutral, universal, and general human conditions.<sup>63</sup> In this context, disability becomes nothing but “a concentrated example that reminds us of the nature of all human beings.”<sup>64</sup>

Tom Reynolds’ theology of vulnerability can be understood as fitting within this category for attributing disability as one of the common experiences and characteristics of human beings. Reynolds argues that the experience of disability reveals the human predicament, especially dependency and vulnerability. Dependency and vulnerability are intricately related as we think of human relationships. On the one hand, as we become dependent on each other, we become vulnerable to “exploitation, loneliness, and suffering.”<sup>65</sup> On the other hand, accepting one’s vulnerability can open up possibilities for “recognizing the other and welcoming them into

---

<sup>59</sup> Creamer, *Disability and Christian Theology*, 93.

<sup>60</sup> M. Mawson, ‘Subjectivity and embodied limits: Deborah Creamer’s disability and Christian theology’, *Journal of Religion, Disability & Health* 17, no. (4) (2013), 410, <https://doi.org/10.1080/15228967.2013.840962>, quoted in Retief and Letsosa, “Models of Disability,” 7.

<sup>61</sup> Retief and Letsosa, “Models of Disability,” 7.

<sup>62</sup> Creamer, *Disability and Christian Theology*, 64.

<sup>63</sup> Retief and Letsosa, “Models of Disability,” 7.

<sup>64</sup> Swinton, “Disability, Ableism, and Disablism,” 447.

<sup>65</sup> Swinton, “Disability, Ableism, and Disablism,” 447.

relationships that are marked by mutual vulnerability and care.”<sup>66</sup> Thus, Reynolds asserts, recognizing one’s vulnerability provides an opportunity for a space of love. In Reynold’s words, “Fundamentally, love involves welcoming another into a space of mutual vulnerability.”<sup>67</sup> For this reason, Reynolds’ asserts that a “focus on vulnerability acts as a theological solvent that dissolves the boundaries between able-bodiedness and disability.”<sup>68</sup>

Stanley Hauerwas holds a similar point. Hauerwas saw that “[t]he powerlessness, dependency, vulnerability, and weakness that mark the lives of people with profound intellectual disabilities reveal fundamental truths about God’s nature”<sup>69</sup> and the status of human beings as creatures, “finite and contingent,”<sup>70</sup> not only a character of the those with intellectual disability, but all of us who are “wholly dependent on God for all things and at all times” before God.<sup>71</sup>

Swinton’s notices the clear distinctiveness of the above Creamer and Reynolds perspectives on limits and vulnerability with regard to liberation theology and the social worldview of disability. And I would add Hauerwers to this group of Creamer and Reynold. Swinton states these theologies are “a strange reversal of the political perspective”<sup>72</sup> especially to liberationist theologies in that they focus on “revelation through the recognition of shared weakness,”<sup>73</sup> whereas the social worldview of disability seeks “empowerment through political participation.”<sup>74</sup> According to Swinton,

From this perspective, the politics of disability and the evils of disablism are not necessarily insignificant, just penultimate. What is ultimate is who we are before God. It is here that disability throws fresh light on the nature of humanness.<sup>75</sup>

---

<sup>66</sup> Swinton, “Disability, Ableism, and Disablism,” 447.

<sup>67</sup> Tom Reynolds, quoted in Swinton, “Disability, Ableism, and Disablism,” 447.

<sup>68</sup> Tom Reynolds, quoted in Swinton Swinton, “Disability, Ableism, and Disablism,” 447.

<sup>69</sup> Swinton, “Disability, Ableism, and Disablism,” 448.

<sup>70</sup> Swinton, “Disability, Ableism, and Disablism,” 448.

<sup>71</sup> Swinton, “Disability, Ableism, and Disablism,” 448.

<sup>72</sup> Swinton, “Disability, Ableism, and Disablism,” 448.

<sup>73</sup> Swinton, “Disability, Ableism, and Disablism,” 448.

<sup>74</sup> Swinton, “Disability, Ableism, and Disablism,” 448.

<sup>75</sup> Swinton, “Disability, Ableism, and Disablism,” 448.

That is, these understandings of disability prioritize to explore theological and relational meaning of phenomenon of disability rather than to intervene or to get involve with social activism. In addition, as Swinton points out, it focuses on finding God's image in recognizing "one's limitations, vulnerabilities, and dependence" rather than associated with traditional image of God "to be independent, powerful, and autonomous."<sup>76</sup>

### Disability as Part of Being God

Since Nancy Eiesland famously asserted that God is disabled, God has acquired various attributes of disabilities such as deaf, blind, crippled, interdependent, and accessible.<sup>77</sup> Premises based on such perspectives include the theology that human beings are created in the image of God. If God is Absolute Being without any disability, this doesn't reflect and affirm human beings with disability. Thus, it traces the image of God and its ultimate progression to normalize the image of human beings in a way that includes and affirms the existence of disability. It reorients the theological value of disability. Thus, in Swinton's words,

Quite simply, the challenge of learning to know, to be with, and care for the retarded [*sic*] is nothing less than learning to know, be with, and love God. God's face is the face of the retarded; God's body is the body of the retarded; God's being is that of the retarded. For the God we Christians must learn to worship is not a god of self-sufficient power, a god who in self-possession needs no one; rather ours is a God who needs a people, who needs a son. Absoluteness of being or power is not a work of the God we have come to know through the cross of Christ.<sup>78</sup>

In that sense, as I mentioned, the psychological function and effect is similar to that of attributing disability to a human person.

---

<sup>76</sup> Swinton, "Disability, Ableism, and Disablism," 448.

<sup>77</sup> Swinton, "Disability, Ableism, and Disablism," 446.

<sup>78</sup> Swinton, "Disability, Ableism, and Disablism," 448.

## **The Human Rights Worldview: Disability as a Human Rights Issue**

The human rights worldview shares many of its tropes with the identity worldview, theological identity worldview, and social worldview. Retief and Letsosa conceive the human rights worldview as the model most similar to the social worldview of disability. For many researchers, the human rights worldview is considered synonymous with the social worldview. Degener saw differences between those two worldviews, largely in two ways: first is that the human rights approach goes beyond explanation of social oppression but provides a constructive proposal and vision, a theoretical framework that disability policy can be based on, as to how to improve the life of people with disabilities.<sup>79</sup> Second, while the social worldview fails to address “the reality of pain and suffering in the lives of some PWDs [people with disabilities], the human rights worldview respects the fact that some PWDs [people with disabilities], are indeed confronted by such challenging life situations and argues that such factors should be taken into account in the development of relevant social justice theories.”<sup>80</sup>

The human rights worldview is similar to the identity worldview and theological identity worldview, especially in that it seeks to affirm disability without degrading or undervaluing it. Perhaps, this has to do with the fact that the human rights worldview historically originated from the religious tradition, more specifically, the Catholic church. To put it simply, the essence of the human rights worldview is its affirmation and protection of human dignity regardless of a person’s status of disability and providing a theoretical foundation to be implemented in legal systems or in society in general, regarding both public and private sectors.

---

<sup>79</sup> Retief and Letsosa, “Models of Disability,” 5.

<sup>80</sup> T. Degener, “A New Human Rights Model of Disability,” in *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary*, ed. V. Della Fina, R. Cera, and G. Palmisano (Cham, Switzerland: Springer, 2017), 47, quoted in Retief and Letsosa, “Models of Disability,” 5.

The prime text of the Human Rights approach is the UN Convention on the Rights of Persons with Disabilities (CRPD), and the agency that I consider to be most important is the Committee on the Rights of Persons with Disabilities. In it, the term disability means an “evolving concept, resulting from the interaction between impairments and attitudinal and environment barriers that hinders their full and effective participation in society on an equal basis with others.”<sup>81</sup> As we can infer by the definition of disability, the human rights approach shares its understanding of disability with the social worldview. The human rights approach of disability follows the social worldview of disability in that it rejects the essentialist understanding of disability and conceives disability as “attitudinal, environmental and institutional barriers that result in situations of vulnerability.”<sup>82</sup>

The notion of ‘human dignity’ plays a significant role in theoretical framework of human rights approach when it comes to understanding people with disability in CRPD as it is in the United Nations Charter and the Universal Declaration of Human Rights.<sup>83</sup> Then, what does dignity mean in this context?

According to Christopher McCrudden, the term ‘dignity’ is used to express appropriately what kind of being we are. There are three basic elements. The first is called the ‘ontological claim’ that “every human being possesses an intrinsic worth, merely by being human.”<sup>84</sup> The second is called the ‘relational’ claim and “is that this intrinsic worth should be recognized and

---

<sup>81</sup> This is from the preamble to the CRPD. “A Human Rights-Based Approach to Disability in Development,” 10, Reliefweb, August 2, 2013, [https://reliefweb.int/sites/reliefweb.int/files/resources/A\\_human\\_rights-based\\_approach\\_to\\_disability\\_in\\_development.pdf](https://reliefweb.int/sites/reliefweb.int/files/resources/A_human_rights-based_approach_to_disability_in_development.pdf) Last Accessed March 8.

<sup>82</sup> United Nations, “Mexico: International and Regional Experts Urge Swift Action to Protect Human Rights Defenders and Journalists,” May 14, 2012, <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25942&LangID=E>; “A Human Rights-Based Approach,” 10–11.

<sup>83</sup> Christopher McCrudden, “Human Dignity and Judicial Interpretation of Human Rights,” *European Journal of International Law* 19, no. 4 (2008): 655.

<sup>84</sup> McCrudden, “Human Dignity,” 679.

respected by others, and some forms of treatment by others are inconsistent with, or required by, respect for this intrinsic worth.”<sup>85</sup> The last element is that the first element of intrinsic worth of human beings needs to be recognized and protected by the state.<sup>86</sup>

McCrudden, a human rights law scholar, notes that the notion of human dignity, a social-political message, was originally a religious teaching of the Catholic church. He explains that “it is noteworthy that the Catholic Church adopted ‘human dignity’ as the rallying cry for the social teaching it developed at the end of the 19th century.”<sup>87</sup> Under the threat of development of communism and “the fear of radical redistribution, class war, and totalitarianism” at the end of the 19<sup>th</sup> century, Pope Leo XIII adopted the notion of “dignity,” “as central to an all-encompassing Catholic social doctrine”<sup>88</sup> and the promotion of the term ‘dignity’ was continued throughout the 20<sup>th</sup> century by Pius XI. Then it was further developed by Pope John XXIII.<sup>89</sup> Later, Jacques Maritain, a French Catholic Philosopher—who participated in the process of drafting the United Nations Charter and the Universal Declaration of Human Rights—put forth effort to employ this notion of human dignity developed in the Catholic tradition, especially the theology of Thomas Aquinas.<sup>90</sup> McCrudden sees that Maritain took on an instrumental role in appropriating the religious and theological notion of human dignity into political life and human relations. This was because,

---

<sup>85</sup> McCrudden, “Human Dignity,” 679.

<sup>86</sup> McCrudden, “Human Dignity,” 679.

<sup>87</sup> McCrudden, “Human Dignity,” 662.

<sup>88</sup> McCrudden, “Human Dignity,” 662.

<sup>89</sup> This was done in Pope John XXIII’s encyclical *Pacem in Terris* and in a key document of the Second Vatican Council *Gaudium et Spes*. McCrudden, “Human Dignity,” 662.

“The approach to dignity developed in this context emphasized the limits of rights in being able to capture the full range of what was necessary to human well-being, the dangers of a conflictual politics, and the need for solidarity between the different interests in society, resulting in a more communitarian conception of human dignity. But dignity was not simply a conception of Man as a political and social animal, and the creation of Man in the image of God remained a key element in its formulation and understanding.” McCrudden, “Human Dignity,” 662.

<sup>90</sup> McCrudden, “Human Dignity,” 662.



[f]or Maritain, dignity was a fact (a metaphysical or ontological status, as well as a moral entitlement), and it was he who brought it into practical international politics in the post-Second World War period.<sup>91</sup>

McCrudden also sees that Maritain’s position as both an academic and a man of affairs allows him to project the notion of human dignity into the wider global community that includes international relations beyond the United Nations.<sup>92</sup>

### **The Legal Worldview of Disability**

The reason why I differentiate the human rights worldview from the legal worldview—even with its shared theoretical foundation—is because of its different focus. As I mentioned, the focal point of the human rights worldview is in its notion of human dignity and in its ability to lay out the notion of human dignity in pragmatically implementable language. The legal worldview, while sharing its foundation, which is the idea of human dignity, focuses on whether it is practically implemented or not.

On July 26, 1990, President George H. W. Bush signed the Americans with Disabilities Act (ADA). Lawrence Gostin, a public health law scholar, explains:

The ADA is a civil rights law that prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public.<sup>93</sup>

What is meant by ‘civil rights’ is that ADA provides civil rights protection to people with disabilities “similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion.”<sup>94</sup> The ADA has a clear purpose—which is to allow and guarantee

---

<sup>91</sup> McCrudden, “Human Dignity,” 662

<sup>92</sup> McCrudden, “Human Dignity,” 662

<sup>93</sup> Gostin, “The American with Disabilities Act at 25,” 2233n27. In *Olmstead v L.C.*, the Supreme Court gave clear expression to this “integration mandate.”

<sup>94</sup> “What Is the Americans with Disabilities Act (ADA)?” ADA National Network, December 2022, <https://adata.org/learn-about-ada>.

“individuals with disabilities to have the same access to all facets of society, to the extent possible, as those without disabilities.”<sup>95</sup> Discrimination becomes “What prevents the full participation of a person, equal treatment and integration”<sup>96</sup> and must be prohibited and eliminated.

In the world of ADA, equality and integration of those with disabilities in society is the ultimate reality as “the ADA embodies the US ideals of equality and integration, affirming that each person is a valued member of society.”<sup>97</sup> Then, how does the legal worldview define disability?

The term “disability” in the Americans with Disability Act (ADA) is taken to mean:

- A physical or mental impairment that substantially limits one or more of the major life activities of such individual;
- A record of such an impairment; or
- Being regarded as having such an impairment.

While Stanley Mutuma, a legal researcher and a lawyer, points out that ADA’s definition is intended to include those “who *actually have* physical or mental impairments that substantially limit one or more major life activities to be included in this definition,”<sup>98</sup> the ADA National Network points out the contentious nature of the concepts of “substantial limitation” and “major life activities.” This is because the Supreme Court and the high court narrowly defined the meaning of “‘major life activity’ to encompass only activities of ‘central importance to most people’s daily lives.’ This resulted in a high and unreasonable threshold for gaining the

---

<sup>95</sup> Gostin, “The American with Disabilities Act at 25,” 2233.

<sup>96</sup> Gostin, “The American with Disabilities Act at 25,” 2232.

<sup>97</sup> Gostin, “The American with Disabilities Act at 25,” 2233–34.

<sup>98</sup> Stanley Mutuma, “The Legal Definition of Disability,” *The East African Review / Les Cahiers d’Afrique de l’Est*, 46, no. 1 (2012), “What Is the Americans with Disabilities Act (ADA)?” <http://journals.openedition.org/eastafrica/434>.

protection of the ADA, even excluding a man diagnosed with mental retardation.”<sup>99</sup> For this reason, the Americans with Disabilities Act Amendments Act (ADAAA) was signed in 2008 and “became effective on January 1, 2009.”<sup>100</sup> ADAAA is meant “to provide protection “to the maximum extent permitted” and provides a nonexhaustive list of “major life activities,” which include caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.”<sup>101</sup>

As we can see in the legal definition of disability, whether a person in this world is identified as disabled or not, depends on medical professionals’ approval. In order for people with disabilities to exercise their legal rights, they need to prove that they are medically disabled. For this reason, the dominant power resides in medically related agencies who can approve an individual’s disabled status. In this regard, the legal worldview of disability shares a lot of similarities with the medical worldview, because the legal understanding of disability is largely based on the biomedical understanding of disability, especially in understanding what disability is. The worldview and the individual’s identity are similar to the medical worldview. Practices include those associated with the medical worldview. Furthermore, it adds practices of narrative telling and filing a document which, to some degree, made them affirm their disabled status. However, the significant difference is, that the legal worldview of disability—with the understanding of disability, according to Mutuma—has a specific goal to

create a civil law framework, with the objective of having the protective framework and aiming to eliminate all forms of discrimination to the class of persons listed therein. It also intended to have persons with disability represented in the main areas, especially as a

---

<sup>99</sup> “What Is the Americans with Disabilities Act (ADA)?” Gostin notes that “overall the Supreme Court’s record on the ADA has been mixed, sometimes expanding coverage for persons with disabilities but at other times restricting coverage.” Gostin, “The American with Disabilities Act at 25,” 2232.

<sup>100</sup> “What Is the Americans with Disabilities Act (ADA)?”

<sup>101</sup> Gostin, “The American with Disabilities Act at 25,” 2232.

result of new advances in medical science, and afforded opportunities in all spheres of life including space frontiers. It was intended to be flexible, with new laws being strengthened and not weakened by future case laws. It was signed by President G.W. Bush and came into operation in 2008.<sup>102</sup>

In many cases, the legal definition of disability is closely related to the social support system because of its function of ‘gatekeeping,’ for example, in connection with disability support income. In order to receive social support a person must prove disability medically and legally.

I mentioned earlier that some worldviews are not clearly classified. For example, the establishment of the ADA is primarily due to the Civil Rights Movement which largely relies on the social constructionist worldview. To some degree, civil disability rights follow the strategy of race and gender. The social constructionist worldview, to some degree, paved the way for the legal worldview of disability to be possible. The primary goal of the legal worldview is to promote full participation and integration. The discrimination must be eliminated, and the law guarantees protection from discrimination caused by a medical understanding of disability. The legal worldview needs the medical understanding of disability in order to make the ADA effective. In this vein, the legal worldview is intricately related to the medical worldview of disability. It accepts and protects the reality that people’s disability becomes a source of discrimination.

---

<sup>102</sup> Mutuma, “The Legal Definition of Disability.”

## Bibliography

- Ali, Carroll A. Watkins. *Survival and Liberation: Pastoral Theology in African American Context*. St. Louis: Chalice Press, 1999.
- Angus, Lynn E., and Leslie S. Greenberg. *Working with Narrative in Emotion-Focused Therapy: Changing Stories, Healing Lives*. Washington, DC: American Psychological Association, 2011.
- Barnartt, Sharon N. "Disability as a Fluid State: Introduction." In *Disability as a Fluid State*, edited by Sharon N. Barnartt, Research in Social Science and Disability 5, 1-22. Bingley, UK: Emerald Group Publishing, 2010.
- Beaudoin, Tom. Review of *Equality and the Family: A Fundamental, Practical Theology of Children, Mothers, and Fathers in Modern Societies* by Don Browning. *Horizon: The College Theology Society* 37, no. 2 (2010): 364–66.
- Bidwell, Duane. "Hope and Possibility: The Theology of Culture Inherent to Solution-Focused Brief Therapy." *American Journal of Pastoral Counseling* 3, no. 1 (1999): 3–21.
- Bischoff, Claire, Elizabeth O'Donnell Gandolfo, and Annie Gardison-Moody, eds. *Parenting as Spiritual Practice and Source for Theology: Mothering Matters*. Cham, Switzerland: Palgrave MacMillan, 2017.
- Black, Kathleen. *A Healing Homiletic: Preaching and Disability*. Nashville: Abingdon Press, 1996.
- Bowler, Kate. *Blessed: A History of the American Prosperity Gospel*. New York: Oxford University Press, 2018.
- Brackett, Marc. *Permission to Feel: Unlocking the Power of Emotions to Help Our Kids, Ourselves, and Our Society Thrive*. New York: Celadon Books, 2019.
- Browning, Don. *Equality and the Family: A Fundamental, Practical Theology of Children, Mothers, and Fathers in Modern Societies*. Grand Rapids, MI: William B. Eerdmans, 2007.
- Browning, Don S. *Fundamental Practical Theology: Descriptive and Strategic Proposal*. Minneapolis: Fortress Press, 1955.
- . *Religious Thought and the Modern Psychologies*. Minneapolis: Fortress Press, 2004.
- Clebsch, William A., and Charles R. Jaekle. *Pastoral Care in Historical Perspective*. Lanham, MD: Jason Aronson, 1994.

- Combs, Gene, and Jill Freedman. "Narrative, Poststructuralism, and Social Justice: Current Practices in Narrative Therapy." *The Counseling Psychologist* 40, no. 7 (2012): 1033–60.
- Cooper, Terry D. *Don Browning and Psychology: Interpreting the Horizons of Our Lives*. Macon, GA: Mercer University Press, 2011), 3.
- Creamer, Deborah. "Theological Accessibility: The Contribution of Disability." *Disability Studies Quarterly* 26, no. 4 (Fall 2006). <https://dsq-sds.org/article/view/812/987>.
- Creamer, Deborah Beth. *Disability and Christian Theology: Embodied Limits and Constructive Possibilities*. New York: Oxford University Press, 2009.
- Creswell, John W., and Cheryl N. Poth. *Qualitative Inquiry and Research Design: Choosing among Five Approaches*. 4th ed. Thousand Oaks, CA: SAGE, 2017.
- Darling, Rosalyn. *Families against Society: Reactions to Birth Defects*. Newbury Park, CA: SAGE, 1979.
- Downey, Taylor N. "Children with Special Needs and the Effect on the Family." Master's thesis, Eastern Illinois University, 2016.
- Eiesland, Nancy L. *The Disabled God: Toward a Liberatory Theology of Disability*. Nashville: Abingdon Press, 1994.
- Everett, Jim A. C., Nadira S. Faber, and Molly Crockett. "Preferences and Beliefs in Ingroup Favoritism." *Frontiers in Behavioral Neuroscience* 9, no. 15 (February 13, 2015). <https://doi.org/10.3389/fnbeh.2015.00015>.
- Flyvbjerg, Bent. "Five Misunderstandings About Case-Study Research." *Qualitative Inquiry* 12, no. 2, (April 2006): 219–45.
- Gallant, J. Paul. "New Ideas for the School Social Worker in the Counseling of Children and Families." *Children and Schools* 15, no. 2 (April 1993): 119–28. <https://doi.org/10.1093/cs/15.2.119>.
- Ganzevoort, R. Ruud. "Forks in the Road When Tracing the Sacred: Practical Theology as Hermeneutics of Lived Religion." Presidential address, International Academy of Practical Theology, Chicago, IL, March 8, 2009. <https://www.ia-practicaltheology.org/wp-content/uploads/2011/11/presidentialaddress2009.pdf>.
- Geertz, Clifford. *The Interpretation of Cultures: Selected Essays*. New York: Basic Books, 1973.
- Gerkin, Charles V. *The Living Human Document: Re-Visioning Pastoral Counseling in a Hermeneutical Mode*. Nashville: Abingdon Press, 1984.
- Goddard, Jay A., Ron Lehr, and Judith C. Lapadat. "Parents of Children with Disabilities: Telling a Different Story." *Canadian Journal of Counselling* 34, no. 4 (2000): 273–89.

Gostin, Lawrence O. "The Americans with Disabilities Act at 25: The Highest Expression of American Values." *JAMA* 313, no. 22 (2015), 2231–35.

Goudie, Anthony, Marie-Rachele Narcisse, David E. Hall, and Dennis Z. Kuo. "Financial and Psychological Stressors Associated with Caring for Children with Disability." *Family System Health* 32, no. 3 (2014): 280–90. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4315505/>.

Graham, Elaine. *Transforming Practice: Pastoral Theology in an Age of Uncertainty*. Eugene, OR: Wipf and Stock, 2002.

Greider, Kathleen J. *Much Madness Is Divinest Sense*. Cleveland: Pilgrim Press, 2007.

Hanton, Paul. *Skills in Solution Focused Brief Counselling and Psychotherapy*. Los Angeles: SAGE, 2011.

Harvey, Clare. "Maternal Subjectivity in Mothering a Child with Disability: A Psychoanalytical Perspective." *Agenda* 29, no. 2 (2015): 89–100.

Hauerwas, Stanley. "Having and Learning to Care for Retarded Children." In *Critical Reflections on Stanley Hauerwas' Theology of Disability: Disabling Society, Enabling Theology*, edited by John Swinton, 149–59. New York: Routledge, 2005.

———. "The Retarded, Society, and the Family: The Dilemma of Care." In *Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped, and the Church*, 161–190. Notre Dame, IN: University of Notre Dame Press, 1986.

Held, Virginia. *The Ethics of Care: Personal, Political, and Global*. Oxford: Oxford University Press, 2007.

———. *Feminist Morality: Transforming Culture, Society, and Politics*. 2<sup>nd</sup> ed. Chicago: University of Chicago Press, 1993.

Hollway, Wendy. "In Between External and Internal Worlds: Imagination in Transitional Space." *Methodological Innovations Online* 6, no. 3. 2011: 50–60. <https://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.690.3724&rep=rep1&type=pdf>.

Hur, Jeongyun. "The Stories of Parents of Children with Mental Disabilities: 'Triumphal' vs. 'Absurd' Narratives." *Journal of Pastoral Theology* 27, no. 1 (2017): 47–62.

Hur, Jeongyun April. "Facing My Own Fears, Finding Wisdom." *Reflections*, Fall 2021. <https://reflections.yale.edu/article/divine-access-disability-and-belonging/facing-my-own-fears-finding-wisdom>.

- Johns, Jennifer. "Transitional Object, Space." In *International Dictionary of Psychoanalysis*, Encyclopedia.com, November 29, 2022. <https://www.encyclopedia.com/psychology/dictionaries-thesauruses-pictures-and-press-releases/transitional-object-space>.
- Kao, Grace. "Prospect for Developing Asian American Christian Ethics." *Society of Asian North American Christian Studies* 3 (2011): 91–102.
- Kelly, Susan E. "A Different Light: Examining Impairment through Parent Narratives of Childhood Disability." *Journal of Contemporary Ethnography* 34, no. 2 (April 2005): 180–205.
- Kim, Hee-kang., Munsun Kang. "A Public Ethic of Care: Eva Kittay and the 'Care Aid Program to Families with Disabled Children' in South Korea." *Korean Political Science Review* 44, no. 4 (2012): 45–72.
- Kingsley, Emily Perl. "Welcome to Holland," 1987, [https://www.dsasc.ca/uploads/8/5/3/9/8539131/welcome\\_to\\_holland.pdf](https://www.dsasc.ca/uploads/8/5/3/9/8539131/welcome_to_holland.pdf).
- Kohlberg, Lawrence. "The Development of Children's Orientations toward a Moral Order: 1. Sequence in the Development of Moral Thought." *Human Development* 51 (2008): 8–20.
- Koolhaas, J. M., et al. "Stress Revisited: A Critical Evaluation of the Stress Concept." *Neuroscience & Biobehavioral Reviews* 35, no. 5 (2011): 1291–1301.
- "KS Studio—Kindred Spirits." Alice Marie Perreault. <https://www.alicemarieperreault.com/ks-studio.html>.
- Kuhn, Thomas S. *The Structure of Scientific Revolutions*. 50th anniv. ed. Chicago: University of Chicago Press, 2012.
- Lalvani, Priya, and Lauren Polvere. "Historical Perspectives on Studying Families of Children with Disabilities: A Case for Critical Research." *Disability Studies Quarterly* 33, no. 3 (2013). [https://dsq-sds.org/article/view/3209\\_](https://dsq-sds.org/article/view/3209_)
- Lamothe, Ryan. "Winnicott and Helplessness: Developmental Theory, Religion, and Personal Life." *The Psychoanalytic Quarterly* 83, no. 4 (2014) 871–96. [https://onlinelibrary.wiley.com/doi/full/10.1002/j.2167-4086.2014.00125.x\\_](https://onlinelibrary.wiley.com/doi/full/10.1002/j.2167-4086.2014.00125.x_)
- Lawrence, Lucie P. "Hardly a Walk in the Park: Examining Disability through a Mother's Eyes." *Journal of Loss and Trauma* 13, no. 6 (2008): 528–40.
- LePera, Nicole. *How to Do the Work: Recognize Your Patterns, Heal from your Past, and Create Your Self*. New York: Harper Wave, 2021. Kindle.
- Lester, Andrew D. *Hope in Pastoral Care and Counseling*. Louisville, KY: Westminster John Knox Press, 1995.



- Lovin, Robin W. *An Introduction to Christian Ethics: Goals, Duties, and Virtues*. Nashville: Abingdon Press, 2011.
- Madigan, Stephen. *Narrative Therapy*. Theories of Psychotherapy. Washington, DC: American Psychological Association, 2010.
- Marshall, Joretta L. "Methods in Pastoral Theology, Care, and Counseling." In *Pastoral Care and Counseling: Redefining the Paradigms*, edited by Nancy J. Ramsay, 133–54. Nashville: Abingdon Press, 2004.
- Mayo, Jessica. "Court-Mandated Story Time: The Victim Narrative in U.S. Asylum Law." *Washington University Law Review* 89, no. 6 (2012): 1485–1522.
- Mayra Ferreras, Marlene. "Sabidurías Insurgentes: Toward a North American Indigenized Pastoral Theology." PhD diss., Claremont School of Theology, 2019.
- McCrudden, Christopher. "Human Dignity and Judicial Interpretation of Human Rights." *European Journal of International Law* 19, no. 4 (2008): 655–724.
- Miller-McLemore, Bonnie. *Also A Mother: Work and Family as Theological Dilemma*. Nashville: Abingdon Press, 1994.
- . *Christian Theology in Practice: Discovering a Discipline*. Grand Rapids, MI: William B. Eerdmans, 2012. Kindle.
- . "Practical Theology." In *Encyclopedia of Religion in America*, edited by Charles H. Lippy and Peter W. Williams, vol. 3, 1739–42. Washington, DC: CQ Press, 2010.
- Morris, Joshua Thomas. "Narratives of Military Moral Injury and Reintegration: Toward a Critical, Liberative Practical Theology." PhD diss., Claremont School of Theology, 2019.
- Moschella, Mary. *Caring for Joy: Narrative, Theology, and Practice*. Theology in Practice. Leiden, Netherlands: Brill Academic Publishers, 2016.
- . "Mary Star of the Sea: The Interplay of Immigration and Religion in Italian Catholic Devotional Practices in the Port of Los Angeles." PhD diss., Claremont School of Theology, 2001.
- Mutuma, Stanley. "The Legal Definition of Disability." *The East African Review / Les Cahiers d'Afrique de l'Est* 46, no. 1 (2012): 27–30. <http://journals.openedition.org/eastafrica/434>.
- Neely-Barnes, Susan L. "Families of Children with Disabilities: A Review of Literature and Recommendations for Interventions." *Journal of Early and Intensive Behavior Intervention* 5, no. 3 (2008): 93–107.
- Neuger, Christie. *Counseling Women: A Narrative, Pastoral Approach*. Minneapolis: Fortress Press, 2001.

- Osmer, Richard. *Practical Theology: An Introduction*. Grand Rapids, MI: William B. Eerdmans, 2008.
- Paterson, Catherine F. "A Short History of Occupational Therapy in Psychiatry." In *Occupational Therapy and Mental Health*, 4th ed., edited by Jennifer Creek and Lesley Lougher, 2–13. Edinburgh: Churchill Livingstone, 2008.
- Patton, John. *Pastoral Care in Context: An Introduction to Pastoral Care*. Louisville, KY: Westminster John Knox Press, 1993.
- Peterson, Lindsay. "A Mother's Love, A Daughter's Courage." Woodland Manor Kennel. Reprint of a *Tampa Tribune* article. Last Accessed December 14. [http://ahts.net/?page\\_id=79](http://ahts.net/?page_id=79).
- Retief, Marno, and Rantsoa Letšosa. "Models of Disability: A Brief Overview." *HTS Theological Studies* 74, no. 1 (2018): 1–8. <https://doi.org/10.4102/hts.v74i1.4738>.
- Root, Andrew. "Practical Theology: What Is It and How Does It Work?" *Journal of Youth Ministry* 7, no. 2 (Spring 2009): 55–72.
- Rubio, Julie. *Family Ethics: Practices for Christians*. Washington, DC: Georgetown University Press, 2010.
- Ruddick, Sara. "On 'Maternal Thinking.'" *Women's Studies Quarterly* 37, nos. 3/4 (2009): 305–8.
- Schneider, Iris K., et al. "The Path of Ambivalence: Tracing the Pull of Opposing Evaluations Using Mouse Trajectories." *Frontiers in Psychology* 17 (2015). <https://www.frontiersin.org/articles/10.3389/fpsyg.2015.00996/full>.
- Schnitker Sarah A., and Robert A. Emmons. "Hegel's Thesis-Antithesis-Synthesis Model." In *Encyclopedia of Sciences and Religions*, edited by Anne L. C. Runehov and Lluís Oviedo, 978. Berlin: Springer. [https://doi.org/10.1007/978-1-4020-8265-8\\_200183](https://doi.org/10.1007/978-1-4020-8265-8_200183).
- Small, Maria. "How Many Cases Do I Need?" On Science and the Logic of Case Selection in Field-Based Research." *Ethnography* 10, no. 1(2009): 5–38.
- Social Security Administration. *Benefits for Children with Disabilities*. Publication. no. 05-10026. Social Security Administration, January 2022. <https://www.ssa.gov/pubs/EN-05-10026.pdf>.
- Stanley, Erinn. "Intellectual Disability and Mystical Unknowing: Contemporary Insights from Medieval Sources." *Modern Theology* 28, no. 3 (July 2012): 385–401.
- Swinton, John. "Disability, Ableism, and Disablism." In *The Wiley-Blackwell Companion to Practical Theology*, edited by Bonnie Miller-McLemore, 443–451. Malden, MA: Blackwell, 2011.
- . *Resurrecting the Person: Friendship and the Care of People with Severe Mental Health Problems*. Nashville: Abingdon Press, 2000.

- Tanner, Kathryn. "The Difference Theological Anthropology Makes." *Theology Today* 50, no. 4 (1994): 567–79.
- Thatamanil, John J. *Circling the Elephant: A Comparative Theology of Religious Diversity*. Comparative Theology: Thinking Across Traditions. Vol. 8. New York: Fordham University Press, 2010.
- Thatcher, Adrian. *Theology and Families*. Malden, MA: Blackwell, 2007.
- Tilburt, Jon C. "The Role of Worldviews in Health Disparities Education." Supplement to *Journal of General Internal Medicine* 25, no. 2 (2010): S178–81.  
<https://pubmed.ncbi.nlm.nih.gov/20352515/>.
- Tilburt, Jon, and Gail Geller. "Viewpoint: The Importance of Worldviews for Medical Education." *Academic Medicine: Journal of the Association of Medical Colleges* 82, no. 8 (2007 August): 819–22. <https://pubmed.ncbi.nlm.nih.gov/17762266/>.
- United Nations. *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. Human Rights, Office of the High Commissioner. December 20, 1993.  
<https://www.ohchr.org/en/instruments-mechanisms/instruments/standard-rules-equalization-opportunities-persons-disabilities>.
- van Harreveld, Frank, Hannah U. Nohlen, and Iris K. Schneider. "The ABC of Ambivalence: Affective, Behavioral, and Cognitive Consequences of Attitudinal Conflict." *Advances in Experimental Social Psychology* 52 (2015): 285–324. <https://doi.org/10.1016/bs.aesp.2015.01.002>.
- Welch, Rosalynde. Review of *Theology and Down Syndrome: Reimagining Disability in Late Modernity* by Amos Yong. *Brigham Young University Studies* 48, no. 2 (2009): 187–91.
- White, Michael. *Maps of Narrative Practice*. New York: W. W. Norton & Co., 2007.
- Woolf, Virginia. *A Room of One's Own*. Boston: Mariner Books, 1989.
- Yong, Amos. *Theology and Down Syndrome: Reimagining Disability in Late Modernity*. Waco, TX: Baylor University Press, 2007.